An investigation of the association between catastrophic thoughts and anxiety in people with respiratory diseases

Thesis

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An investigation of the association between catastrophic thoughts and anxiety in people with respiratory diseases.

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ABSTRACT

The purpose of this study was to investigate whether the cognitive model of panic may explain the high levels of anxiety that have been reported amongst people with Chronic Obstructive Pulmonary Disease (COPD) (Carr et al, 1994). In previous research, cognitive variables, assessed on general measures of catastrophizing (such as the Agoraphobic Cognitions Questionnaire), have been shown to be strongly predictive of anxiety in people with COPD, regardless of severity or duration of the respiratory disease. One of the aims of this study was to develop a questionnaire to elicit specific cognitions in response to a range of COPD-related symptoms presented in different situations. Favourable reliability and validity were demonstrated for the questionnaire, and its completion by 37 people with COPD produced a range of cognitions of differing severity. High levels of anxiety (assessed using the Hospital Anxiety and Depression scale) were found in the group (more than 27%). More severe catastrophic thoughts were found to be strongly predictive of greater anxiety, particularly for specific anxiety ratings on the new questionnaire, and this relationship was more significant when cognitions and anxiety were elicited by symptoms presented in 'unsafe' situations. Severity and duration of illness were not significant predictors of anxiety, but social support was strongly predictive of generalized anxiety. In the light of the adverse consequences of anxiety with regards to appropriate coping with respiratory disease, an exploration of the use of cognitive techniques in therapy is suggested.

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Section 1

INTRODUCTION

1. INTRODUCTION

Respiratory disorders, such as asthma, emphysema, and chronic bronchitis, which result in chronic breathing difficulties, represent a major medical and social problem in Europe and the USA today (Carr, Lehrer, Rausch, & Hochron, 1994; Kaptein, Dekker, Van der Waart, & Gill, 1988). The Health of the Nation document specifically identified asthma as a substantial cause of ill health, with national targets likely to be set for respiratory health in the future (HMSO, 1991). A number of studies have reported that patients suffering from respiratory disorders show higher levels of psychological disturbance than those in the general population, with reports of significant emotional, behavioural, and psychosocial deficits (Burns & Howell, 1969; Carr, Lehrer & Hochron, 1995; Greenberg, Ryan, & Bourlier, 1985; Porzelius, Vest, & Nochomovitz, 1992), although the exact nature and prevalence of these problems is unclear and research is still relatively new in this area. In recent years, clinicians and researchers have identified the potential importance of psychological aspects of respiratory diseases in the treatment and management of these problems. For example, the literature suggests that high levels of anxiety, depression and social isolation amongst this population may contribute to inappropriate over-use of medication, and more frequent hospital admissions (Carr *et al.*, 1995; Kinsman, Dirks, Jones & Dahlem, 1980; Lehrer, Sargunaraj, & Hochron, 1992).

Following a brief explanation of general characteristics of chronic breathing disorders, there will be a discussion of research studies which have looked at the prevalence of anxiety and panic in this population. Although depression is also a feature often reported in studies with patients with respiratory impairment (Lehrer *et al.*, 1992) it will not be a major focus of this study. Various models that could account for reportedly high levels of anxiety in people with respiratory disease

are presented briefly, with discussion of factors that provide evidence for and against each model. Particular emphasis will be given to the application of cognitive theory to the experience of anxiety and panic, and the limitations of the research to date, in providing firm evidence for or against this theory.

1.1 DEFINITION OF RESPIRATORY DISORDERS

1.1.1 Chronic Obstructive Pulmonary Disease (COPD) refers to a number of chronic respiratory disorders of unknown aetiology that are characterised by persistent slowing of airflow during forced expiration. The disorders commonly associated with COPD are asthma, chronic bronchitis and emphysema; the common denominator of these disorders is expiratory flow obstruction due to narrowing of airways, although the cause is different in each disorder (Kaplan, Reis & Atkins, 1985; Lee, Graydon & Ross, 1991). The chronicity of the condition may result in incapacitation of the patient physically, psychologically, and socially (Lee *et al.*, 1991), causing shortness of breath, (dyspnea), cough, and progressive disability (Agle & Baum, 1977).

Asthma is the most extensively explored respiratory disorder by psychologists. Only very recently have chronic bronchitis, emphysema, and other disorders, been studied in more detail, and as such, it is a largely unexplored field for health psychologists.

1.1.1.1 Asthma

> 'Asthma is a disease characterised by an increased responsiveness of the airways to various stimuli and manifested by slowing of forced expiration which changes in severity either spontaneously or as a result of therapy' (American Thoracic Society, 1962; cited in Kaptein *et al.*, 1988).

This description highlights two of the four characteristics of asthma - the hyper-reactivity of the airways and the reversibility of the disorder. Three mechanisms (Kossack, 1986; cited in Creer & Wigal, 1989) that have been proposed to account for asthma are:

1. **Allergens** in the environment causing bronchospasm
2. **Nonspecific irritants** that stimulate nerve receptors in the respiratory tract.
3. **Infections** that cause inflammation and swelling of the mucosa, releasing excessive mucus and blocking the bronchial tube (Emmelkamp & van Oppen, 1993).

Reversibility of asthma is particularly important, distinguishing it from other respiratory conditions such as emphysema. While many patients show complete reversibility of their symptoms, others do not, even with intensive therapy. Frequency of asthmatic episodes may be intermittent, varying from patient to patient, and for each patient, from time to time. Severity of individual attacks, is also variable. Asthmatic episodes can range from a mild wheeze to fatal occlusion of the airways. There is no standard way of classifying a patient as having mild, moderate, or severe asthma, despite the fact that these terms are used frequently throughout the literature (Creer & Wigal, 1989).

1.1.1.2 Chronic Bronchitis - This condition is associated with prolonged exposure to non-specific bronchial irritants, primarily smoking, and is accompanied by the hypersecretion of mucus in the airways. In many studies, the production of sputum or presence of a cough on most days for at least three months of the year has frequently been adopted as a criterion for diagnosis. The predominant result of excess mucus production is reduced airflow; this is characterised by coughing, wheezing, and dyspnea (shortness of breath). These symptoms are similar to those displayed by patients with chronic asthma, and there are sometimes mistakes in diagnosis (Creer & Wigal, 1989; Kaplan *et al.*, 1985).

1.1.1.3 Emphysema - This is defined by the American Thoracic Society (1962; cited in Kaptein *et al.*, 1988) as an 'abnormal enlargement of the air spaces distal to the terminal non-respiratory bronchiole, accompanied by destructive changes of the alveolar walls'. It is at the alveoli that oxygen enters the bloodstream, and carbon dioxide is collected to exhale from the lungs. As alveolar walls break down, individual alveoli merge, and the lung gradually loses its elasticity. Air becomes trapped in the damaged areas and the lungs become inflated and enlarged (Kaplan *et al.*, 1985). The permanent and abnormal enlargement of the alveoli also lessens the amount of lung surface available for oxygen uptake from inhaled air. As in chronic bronchitis, symptoms include coughing, dyspnea and wheezing.

1.1.2 Epidemiology

Epidemiological data indicate that the incidence and prevalence of COPD, and asthma in particular, varies considerably in different parts of the world, with rates of less than 1% in Gambia and Japan, and between 5% and 8% in the Netherlands, Great Britain and the USA (Kaptein *et al.*, 1988). In Australia, 20% of children and 10% of adults have asthma at any one

time - a rate more than twice as high as those reported in the USA and Europe (Bauman, 1993). Indications are that both prevalence and mortality rates for COPD are rising (Brooks, Richards, Bailey, Martin, Windsor, & Soong, 1989; Buist, 1989).

The economic, psychological, social and medical consequences of COPD can be severe (Janson-Bjerklie, Ferketich & Benner, 1993). In the Netherlands, COPD is third on the list of mortality causes and the first reason for absence from work in adults (Kaptein *et al.*, 1988). The economic costs are therefore quite considerable, and its incidence is certain to rise in the coming decades, primarily as a result of tobacco smoking. In 1986, COPD-related deaths in the USA represented 3.5% of all deaths in the country. In the UK, asthma-related deaths increased by over 20% in the 5 years between 1980 and 1985 (Burney, 1986).

In addition to the physical symptomatology characteristic of COPD, it has long been recognised that a number of psychological factors are also associated with chronic respiratory diseases.

1.1.3 Psychological Factors Associated with COPD - COPD patients have been reported by a number of authors to consistently show higher than average levels of anxiety, depression, and social isolation (e.g. Kaptein *et al.*, 1988; Maes & Schlosser, 1988; Yellowlees, Alpers, Bowden, Bryant, & Ruffin 1987). Patients suffering from asthma frequently report pessimism about their illness and future, and subgroups of patients have reported a high level of psychological stigma.

Early studies showed that patients with respiratory diseases who suffered from breathlessness disproportionate to the degree of physiological impairment, had more psychological symptoms,

including anxiety and depression, than patients whose breathlessness was consonant with the results of pulmonary tests (Burns & Howell, 1969). Kinsman, Luparello, O'Banion, & Spector (1973) found that 42% of asthmatics frequently rated symptoms of a panic/fear factor as occurring with their asthma attacks. These same symptoms are also frequently reported by people with bronchitis and emphysema (Kinsman, Fernandez, Schocket, Dirks & Covine, 1983). A review of the psychological aspects of rehabilitation that were important to patients with COPD found that anxiety, depression and bodily preoccupation were common problems (Agle & Baum, 1977). The subjective experience of anxiety in patients with COPD was reported to result from fear of dyspnea, suffocation, and even death, and that when anxiety was disproportionately high, patients may avoid realistic physical activity, contributing to functional incapacitation, and impeding successful rehabilitation.

Yellowlees and colleagues (Yellowlees *et al.*, 1987) assessed, both medically and psychiatrically, 50 consecutive patients with chronic airflow obstruction who were admitted to a respiratory unit. A high rate of psychiatric morbidity (58%) was detected following structured interview, with panic and other anxiety disorders (24%) being particularly prevalent. A subsequent study with 49 patients with COPD reported a similarly high prevalence of psychiatric morbidity (Yellowlees, Haynes, Potts & Ruffin, 1988). Patients in these studies were reported to be a greater strain on hospital resources than other, less anxious patients with COPD, with more frequent admissions, and generally staying in hospital for twice as long.

Another study by Karajgi, Rifkin, Doddi & Colli (1990), found that 18% of 50 consecutive COPD patients attending a respiratory outpatient clinic, had a present or past diagnosis of mood disorder, a figure consistent with epidemiological studies in the general population. However,

lifetime prevalence figures for anxiety disorders (16%) and panic disorder (8%) were interesting, as, although figures for anxiety were comparable to those in the general population, the level for panic disorder was 5 times higher than in the general population. Their findings were lower than those found by Yellowlees *et al* (1987) and Yellowlees *et al* (1988), who included in their study a number of people who described having had 'near-death' experiences in the past, possibly making them more prone to panic. The higher prevalence of anxiety disorder in the Yellowlees et al study (1988) may also be due to the use of the Diagnostic Interview Schedule (Yellowlees et al, 1988), which is considered over-inclusive for anxiety disorders. There may also have been a selection bias in participant involvement as the studies were carried out in respiratory clinics where people had come with specific problems in coping with their respiratory disorders.

More recently, van Peski-Oosterbaan, Sponhoven, Willem van der Does, Willems & Sterk (1996) reported that 9% of their sample of 123 patients with asthma had panic disorder - a figure higher than in the general population, but comparable to the rate observed in non-asthmatic medical populations involved in their study. However, in this study, moderate rates of anxiety were not reported, so a conclusion about total rates of anxiety in their sample cannot be made.

Despite the wide range of reported incidence of anxiety and panic described in the literature and the associated methodological problems of these studies, it does appear that anxiety disorder and panic are present in a significant number of people with COPD, to an extent that this additional psychiatric disturbance may inhibit adequate coping and engagement in treatment regimes and programmes (Carr *et al.*, 1994; Kaptein *et al.*, 1988; Porzelius *et al.*, 1992). Various models have been proposed to explain the development of anxiety and panic in this patient group, and these will be discussed briefly below.

1.2 MODELS TO EXPLAIN HIGH PREVALENCE OF ANXIETY

1.2.1 Learned Experience

Breathing is a basic physiological function, and acute dyspnea is one of the most frightening human experiences. In COPD, anxiety disorders and panic are characterised by hyperventilation and phobic avoidance of certain situations, such as being outside the home without an inhaler or a companion. Fear, hyperventilation, and panic tended to occur in the study by Yellowlees and colleagues (Yellowlees *et al.*, 1987) when patients were alone, enclosed, or had worsening airways obstruction. Phobic avoidance of these situations was hypothesised to lead to further anxiety and the development of a vicious circle of fear, hyperventilation, panic, and avoidance, mediated primarily be anticipatory anxiety. Such behaviour was observed to result in significant handicaps, with social and functional restriction, and the authors proposed that asthmatic patients may develop phobias for situations in which they have had an attack. A number of studies have evaluated the use of systematic desensitization and relaxation focusing on the anticipatory fear of attacks, although evidence supporting this approach for anxiety reduction and improved lung function is limited (Emmelkamp & van Oppen, 1993).

1.2.2 Biological

One hypothesis is that panic attacks may be secondary to certain physiological changes, as it has been noted that episodes of panic can be induced by hyperventilation, or rebreathing carbondioxide (Gorman, Askanazi & Liebowitz, 1984). It is possible that this occurs in patients with chronic airflow obstruction as they often exhibit acidaemia, which occurs when too much carbondioxide is present in the lungs. This biological hypothesis, when combined with the fear and learned phobic avoidance of certain situations, could account in part for the common features of panic and anxiety in some patients with COPD.

1.2.3 Dyspnea Fear

The dyspnea-fear theory predicts that patients with panic disorder experience 'fear in direct response to severe hyperventilation induced dyspnea in the context of little or no perceived control over the cause of dyspnea' (Ley, 1989, pp.549). The high prevalence of anxiety and panic symptoms among pulmonary disease patients relative to the general population suggests that breathing abnormalities (dyspnea) may play a key role in the experience of panic attacks and panic-fear in this population (Carr, Lehrer & Hochron, 1992; Kellner, Samet & Pathek, 1992). In early studies of respiratory disease, changes in observed anxiety as well as depressed mood were reported with an increase in dyspnea (Dudley, Verhey, Masuda, Martin, & Holmes, 1969). The dyspnea-fear model emphasizes the importance of the frequency or intensity of symptoms with which the patient frequently copes, many of which can be life-threatening, stressing the realism of the belief that the experience of dyspnea may lead to suffocation or death.

1.2.4 Cognitive model

Phenomenologically, some of the symptoms of panic disorder are very similar to the symptoms of respiratory diseases, such as dyspnea and choking (Spinhoven, Ros, Westgeest, & van der Does, 1994), and a high degree of avoidance of certain situations where breathing pattern may be disrupted or temporarily obstructed (Carr *et al.*, 1992; Kinsman *et al.*, 1980; Yellowlees *et al.*, 1987). For this reason, some authors have investigated the relationship of anxiety and panic to COPD using models from psychiatric practice. Cognitive models of panic propose that panic results from misinterpretation of physiological or physical symptoms and sensations (Beck, 1987; Clark, 1986). An enduring tendency to make catastrophic interpretations of a variety of bodily symptoms and sensations intensifies the unpleasant somatic sensations associated with fear, which in turn increases catastrophic cognitions, resulting in a vicious cycle. COPD patients

are a population whose physical condition presents them with chronic, or chronic-episodic exposure to those physiological sensations associated with the onset of panic (e.g. shortness of breath, palpitations, sweating, numbness or tingling sensations, etc). The cognitive theory of panic presented by Clark (1986), would suggest that only patients who also experience catastrophic cognitions in addition to the physiological sensations associated with COPD will be more susceptible to panic as it is the presence of catastrophic interpretations that is the key factor. However, the susceptibility of this group to panic may be heightened as the frequency of associated physiological sensations in this group might be a vulnerability factor and, given the presence of catastrophic cognitions associated with panic, could result in a higher frequency of panic attacks than in the general population (Porzelius *et al.*, 1992). Support for the cognitive theory of panic comes from studies in which catastrophic cognitions were modified to produce positive or negative changes in affect in patients' response to hyperventilation (Salkovskis & Clark, 1990).

1.3 INVESTIGATIONS OF MODELS

Studies have tried to explain high levels of anxiety and panic in patients with COPD, by differences in pulmonary function or in cognitions between asthmatics with panic disorder and those without. However, a study by Spinhoven, Onstein, & Sterk, (1995) found no relationship between signs of actual airways obstruction and panic symptoms in panic disorder patients without asthma, which suggests that other factors, including specific cognitions about the consequences of experiencing symptoms may be more relevant in providing an explanation for the presence of anxiety in people with and without asthma. Although biological and learned experience models have been put forward as a possible explanation for anxiety and panic in

patients with respiratory diseases, there has been little investigation of their adequacy, with more focus in the literature on the dyspnea-fear theory and cognitive theory.

1.3.1 Dyspnea-fear model versus cognitive model

Some studies have been carried out with the aim of assessing whether the dyspnea-fear theory may explain the presence of anxiety and panic amongst patients with COPD (Carr *et al.*, 1992; Kellner *et al.*, 1992). In their study with 24 asthmatics and 10 panic disorder patients, Carr *et al.* (1992) reported that fear of dyspnea accounted for breathing-related anxiety amongst the asthma patients, and that anxiety and panic symptoms in asthma, but not panic disorder, were mediated predominantly by the experience of dyspnea. However, there were several limitations to this study, the first being the small sample sizes. Selection biases may have been present, as the asthmatic patients who volunteered for the study may have been experiencing more stress and anxiety than a typical population of asthmatics, as they were already involved in a relaxation group. Most importantly, the study did not directly measure panic-related cognitions, and so the relative contribution of these to anxiety and panic could not be assessed.

In a revised study, Carr *et al.* (1995) determined the predictive strength of cognitive variables in direct comparison to dyspnea-related variables, with a larger sample of patients with asthma, testing Clarks' cognitive model of panic disorder (Clark, 1986) as a model for predicting panic-fear in asthma. In this model, the frequency and intensity of symptoms is hypothesised to be inadequate for the development of anxiety, in the absence of a tendency to misinterpret or catastrophise about symptoms. Regression analysis showed that cognitive variables predicted a significant amount of the variance on scales of panic-fear and anxiety, even after controlling for asthma variables. In contrast to their earlier findings (Carr *et al.*, 1992), frequency and severity

of asthma symptoms were not associated with generalized panic-fear when cognitive variables were controlled for, providing strong evidence that the level of pulmonary impairment is not a strong predictor of panic-fear in the absence of catastrophic or irrational thoughts. They concluded that 'measures of catastrophic cognitions are a better predictor of anxiety than is a measure of asthma symptomatology', and suggest that 'cognitions therefore represent an important target in psychological interventions aimed at improving the long-term course of asthma' (Carr *et al.*, 1995).

Porzelius *et al.* (1992) investigated the relationship of catastrophic cognitions, physical symptoms, and panic in a population whose presenting problem was respiratory dysfunction (physical symptoms) rather than panic. Their study with 48 COPD patients showed that patients who experienced impaired respiratory functioning and shortness of breath were highly likely to experience panic. While all participants experienced physiological sensations associated with panic, only 37% had experienced panic attacks, these patients expressing a significantly higher frequency of fear-provoking thoughts. In those people who did experience panic, there was a strong association between physical sensations and agoraphobic cognitions, while degree of respiratory impairment and level of general anxiety or depression was less significant. as in the study by Carr and colleagues (Carr *et al.*, 1995), panickers did not differ from nonpanickers in severity of pulmonary disease or severity of shortness of breath, but were distinguished by more frequent agoraphobic cognitions and greater fear of body sensations. This data suggests that COPD patients experience panic attacks because the symptoms are interpreted catastrophically, and not because of higher generalized anxiety, depression, or more severe pulmonary impairment.

Carr and colleagues (Carr *et al.*, 1994) investigated psychological vulnerability (anxiety sensitivity) to panic related phenomena. Anxiety Sensitivity reflects an individuals' concerns about the consequences of experiencing anxiety related symptoms, and is defined as a personality trait increasing an individuals' conditionability to fear. Asthmatics experience more symptoms of dyspnea and hyperventilation than do non-asthmatics, and sometimes these symptoms can be associated with life threatening exacerbations; however, not all asthmatics experience panic. Thus panic attacks in this population were predicted to depend more on concerns about these sensations (anxiety sensitivity) than on the actual severity of the illness (objective measures of pulmonary function). They found that the experience of severe and frequent panic attacks was significantly more common among both asthmatics and nonasthmatics who expressed negative beliefs about somatic sensations (high anxiety sensitivity), and that these results were not due to differences in pulmonary function. This strongly supports Clark's cognitive model where catastrophic misinterpretations of somatic sensations are deemed necessary for development of panic disorder. Analysis of panic-related cognitions revealed that asthma alone - a disease characterised by frequent and severe bouts of dyspnea, wheezing and hyperventilation - was not associated with elevated fears of bodily sensations, or with irrational beliefs about the consequences of anxiety, or with catastrophic cognitions. On the other hand, patients with asthma and panic disorder had significantly higher ratings on these measures relative to asthmatics without panic disorder. So, although the incidence of panic disorder is reportedly higher among those with asthma than among the general population (e.g. Yellowlees *et al.*, 1987), this cannot be explained simply by the presence of asthma or COPD, or by the degree of pulmonary impairment, and its associated symptoms. Rather, the findings concur with Porzelius *et al.*, (1992) and Carr *et al.*, (1995) in providing

evidence that the occurrence of panic attacks among individuals with COPD is due to misinterpretations of bodily sensations, as in the general population.

1.4 CLINICAL CONSEQUENCES OF CATASTROPHIZING

The studies described above emphasise the importance of catastrophic cognitions in relation to anxiety in patients with COPD. Studies in other chronic illness population groups (Petrie, Moss-Morris & Weinman, 1995; Smith, Follick, Ahern, & Adams, 1986; Smith, Peck, Milano, & Ward, 1988) have pointed to the particular role of catastrophic thinking in influencing overall disability levels, with severe catastrophization about symptoms of arthritis and lower back pain being associated with higher levels of disability and depression. In a study with patients suffering from chronic fatigue syndrome, (CFS), Petrie *et al.* (1995) showed that individual differences in beliefs and cognitions about CFS influenced disability levels through the limits and boundaries sufferers set in their level of functioning. They found that differences in catastrophic thinking in their sample could not be explained by differences in length of illness or in the level of psychological disturbance in the two groups, concluding that it may not be the number or seriousness of the CFS symptoms, but their meaning to catastrophizers that is the critical factor in limiting functioning.

A recent review of cognitive processes in chronic pain patients (Smith *et al.*, 1986) concluded that catastrophizing is the most important factor in poor coping with chronic conditions, and is strongly related to greater disability. Catastrophizing has both direct and indirect effects on the physiological processes that may maintain or even exacerbate a chronic disorder, for example, in chronic pain, negative cognitive interpretations can cause direct effects by increasing autonomic or nervous system arousal. Indirect effects can occur as a result of reduced physical activity.

It is important to bear in mind that cognitive factors have a uniquely significant role in patients suffering from chronic compromised respiratory functioning. The physiological sensations associated with COPD are generally chronic, often progressive, and may trigger more severe problems. Catastrophic interpretations of bodily sensations cannot necessarily be termed 'misinterpretations' since the hyperventilation and panic which can result from these cognitions could really produce the health risk suggested by the catastrophic thoughts. It would therefore be important in treatment, to carefully assess the nature and extent of cognitions relating to COPD symptomatology. Modification of catastrophic cognitions may be important if they are shown to cause excessive anxiety to the patient, resulting in an inability to cope adequately and appropriately with symptoms. However, a certain amount of anxiety could actually be helpful in alerting patients to a potentially life-threatening exacerbation of breathing problems (Kinsman *et al.*, 1983).

1.5 SUMMARY OF RESEARCH AND IMPLICATIONS FOR THIS STUDY

From the literature discussed above, it is apparent that there is great variation between the findings of different researchers. Figures reported for the prevalence of anxiety and panic disorders vary from 9% - 37% (Karagji *et al.*, 1990; Porzelius *et al.*, 1992; van Peski-Oosterbaan *et al.*, 1996; Yellowlees *et al.*, 1987). These differences appear to be due to different criteria for assessment and diagnosis of anxiety and panic, different methodologies used in studies, and possible selection biases amongst patients who took part in each of the studies (Carr *et al.*, 1995; van Peski-Oosterbaan *et al.*, 1996). Despite these differences, the widespread reporting of higher than normal levels of anxiety amongst people with COPD, and asthma in particular (Kinsman *et al.*, 1979; Kinsman *et al.*, 1983), appears to be an accepted factor associated with respiratory disorders. The consequences of experiencing clinical levels of anxiety have been demonstrated

to be detrimental to patients' ability to cope adequately with their respiratory disease, resulting in inappropriate over-use of steroid medications, excessive use of as-needed medications, and more frequent and longer hospital admissions (Dahlem, Kinsman & Horton, 1977; Dirks, Fross & Evans, 1977; Kinsman *et al.*, 1980). These effects are independent of objectively measured pulmonary impairment. Engagement in rehabilitation programmes has been reported to suffer, with patients being unable to utilise adequate coping strategies, and high drop-out rates amongst this subgroup of COPD sufferers (Kaptein *et al.*, 1988).

Various models have been explored in an attempt to understand why some patients with chronic respiratory conditions may be more susceptible to developing anxiety and panic disorders than people without these conditions. The high prevalence of anxiety and panic symptoms among pulmonary disease patients relative to the general population suggests that breathing abnormalities play a key role in the experience of panic attacks and panic-fear in this population. To date, the most extensively explored theories are the dyspnea-fear theory (Lee *et al.*, 1989) and the cognitive model of panic (Clark, 1986). Studies have shown that in the absence of catastrophic thoughts, dyspnea-fear and severity of symptoms do not adequately explain anxiety and panic in patients with COPD (Carr *et al.*, 1995; Porzelius *et al.*, 1992; van Peski-Oosterbaan *et al.*, 1996). In the study by Porzelius and colleagues (Porzelius *et al.*, 1992) patients with COPD and panic disorder reported a high frequency of fear-provoking thoughts in contrast to COPD patients who did not panic, while there was no difference between the groups in severity of pulmonary impairment.

Despite evidence that the presence of catastrophic cognitions appear to be a necessary factor for the experience of panic and anxiety in COPD, there are no studies to date that have attempted to

show the causal role of specific cognitions relating to symptoms of respiratory disease in predicting anxiety and panic reactions among pulmonary disease patients. There are also no studies which have described the precise content and focus of the catastrophic thoughts identified as being present through questionnaires such as the Agoraphobic Cognitions Questionnaire (Chambless, Caputo, Bright, & Gallagher, 1984). Self-report measures of these cognitions may provide a useful insight into these, and hence a firm focus for treatment aimed at modifying the content of these thoughts. In studies of panic disorder (Clark, 1986), catastrophic thoughts in relation to somatic symptoms of anxiety and panic, focus on the negative consequences of those symptoms and include thoughts of suffocation, loss of control and dying. Clinical experience suggests that maybe the precise content of thoughts in COPD may be more specifically related to respiratory disease. If catastrophic thoughts are identified amongst a group of patients with COPD, then it may be reasonable to predict that these people would also have significant levels of both illness-focused anxiety and general anxiety.

One of the aims of this study is to ascertain the presence and severity of catastrophic thoughts about the consequences of experiencing symptoms of respiratory disease amongst a group of outpatients with COPD, and whether more severe catastrophic thoughts are associated with higher levels of anxiety. The precise content and focus of thoughts in relation to these symptoms, will also be determined, and the relationship of catastrophic thoughts to anxiety will be explored. The relative contribution of variables in prediction of anxiety, such as illness severity and duration of COPD (Carr *et al*, 1995; Porzelius *et al.*, 1992), and age (Maes & Schlosser, 1988) will be explored. Another important variable which will be investigated in addition to those outlined above is the potential contribution of social support and its relationship to anxiety. Perception of social support has been shown to bear a strong negative relationship to

anxiety and depression, and to have important implications for health status and mortality (Sandler and Barrera, 1984; Sarason, Shearin, Pierce & Sarason, 1987).

The first aim of this study is to develop a questionnaire that will be appropriate for use in ascertaining the presence, content and severity of catastrophic thoughts in relation to symptoms associated with COPD. Once this questionnaire has been developed, and its' psychometric properties assessed, the following hypotheses will be tested:

Hypothesis 1: A high prevalence of clinically significant anxiety will be found in a sample of COPD patients.

Hypothesis 2: The presence of more severe catastrophic thoughts will be related to higher levels of (a) generalised anxiety (HADS anxiety) and (b) specific anxiety ratings.

Hypothesis 3: In situations that are perceived as being more threatening ('unsafe'), participants are more likely to, (a) have more severe catastrophic thoughts; and (b) report higher levels of anxiety in response to symptoms, than in situations perceived as less threatening.

Hypothesis 4: Severity of catastrophic thoughts (open-ended responses) will predict more of the variance in anxiety than other variables associated with anxiety, including disease severity, duration of COPD, age, and satisfaction with social support.

Section 2

METHOD

2. METHOD

As no questionnaire existed which specifically assessed cognitions related to COPD symptomatology, one of the aims of the study was to develop a questionnaire which would do this. Information was gathered through interview with 6 COPD patients, and details of this, and the development of the questionnaire content and format is described below, in addition to information on the main study. Assessment of the reliability and validity of the resulting questionnaire is described in the Results section.

2.1 PARTICIPANTS

2.1.1. Initial Investigations: People attending the Pulmonary Rehabilitation Programme at the hospital where the study was based, were approached by letter (Appendix I) which included a consent form (Appendix II), and a prepaid envelope for the return of completed consent forms.

2.1.2. Main Study: Potential participants were selected from the following groups: (1) people who had attended past Pulmonary Rehabilitation Programmes, (2) people who attended the Chest Clinic at the hospital where the study was based, and (3) people who attended a Respiratory Clinic at a General Practice in the local town. All potential participants were invited to take part in the study via an information letter (Appendix III), which included a consent letter (as above), and a prepaid envelope for its return. Potential participants who did not reply to the original letter within 4 weeks were sent a reminder letter (Appendix IV).

2.1.3. Both Studies: Criteria for inclusion for both studies was a diagnosis of COPD (including asthma, bronchitis and/or emphysema), and participants had to be aged over 18 years. Potential participants were excluded if they had other significant physical illness, or were known to have significant mental health problems. This was ascertained by the Consultant Chest Physician and the General Practitioner involved, who were familiar with their patients' medical histories.

2.2 DESIGN

2.2.1 Initial investigations were completed as a structured interview

2.2.2 Main Study was a within subjects design, using three standardized questionnaires, one new measure designed following initial investigations, and a background information sheet.

2.3 MEASURES

2.3.1. Development of the questionnaire through initial interviews:

Table 1 gives demographic data for the six participants who took part in the initial investigations.

Table 1: Demographic data for participants who took part in initial interviews

	Number	Mean age - years (SD)[a]	Mean duration of COPD - years (SD)
Female	4	65.0 (8.2)	6.0 (3.7)
Male	2	58.0 (7.0)	6.0 (5.0)
Total	6	62.7 (8.5)	5.8 (4.0)

[a]Standard Deviation

The age-range of the participants was 51-79 years, with a mean of 62.7 years (SD=8.5) for the whole sample. Of the six participants, four (66%) were female and two (33%) were male. All participants in the pilot study had a diagnosis of COPD, and within this diagnosis, two had asthma and four had emphysema. The duration of illness for the group ranged between one and

11 years (mean,5.8 years; sd, 3.98). All had participated in a Pulmonary Rehabilitation group over the year preceding the study.

2.3.2. Initial gathering of information. This involved completion of a structured interview designed by the author (Appendix V), to assess:

(i) Symptoms commonly experienced in relation to COPD (based on the Asthma Symptom Checklist (Kinsman *et al.*, 1973), and the Bronchitis and Emphysema Symptom Checklist (Kinsman *et al.*, 1983));

(ii) Thoughts relating to the experience of those symptoms;

(iii) Situations and activities avoided in order to avoid experiencing those symptoms.

In addition, a list of 14 different situations discussed at initial interview, was given to 14 healthcare professionals with asthma, who rated them on a scale of 1-4 for their perceived safety in the event of experiencing breathing difficulties related to their asthma, with 1 being most 'safe', and 4 being most 'unsafe'.

The information from this initial study was used in development of the 'Interpretation of Breathing Problems Questionnaire' used in the main study (see below).

2.3.3. Main Study:

2.3.3.1 Interpretation of Breathing Problems Questionnaire (IBPQ): This 14 item questionnaire (Appendix VI) consisted of 14 items, comprising seven symptoms commonly associated with COPD, each presented in two different situations. Initial interviews suggested that the type of situation in which symptoms were experienced may be important. Hence, following statistical testing on the ratings of safety, seven 'safe' and seven 'unsafe' situations were included in the

questionnaire items to explore the influence of situation on catastrophic thoughts and anxiety. Presentation of the items within the questionnaire was randomised. For each item, there was a brief description of a symptom experienced in one of 14 situations, (for example, 'You are on a long walk alone, and you begin to feel short of breath') which was then followed by three open-ended questions; 'What would you do in this situation?', 'What thoughts go through your mind?', and 'What is the worst thing you think may happen to you?'. These questions were designed to elicit any associated catastrophic cognitions. Participants were asked to write the first thing that came into their mind in response to these questions. There then followed three visual rating scales from 1-10, with instructions to rate (in relation to the information presented in each item) (i) their anxiety (where 1 is no anxiety and 10 is maximum anxiety), (ii) their belief that they will become ill (where 1 is no illness and 10 is total belief that they will become ill), and (iii) their belief that they will die, (where 1 corresponds to 'definitely won't die' and 10 corrsponds with 'definately will die'). Finally, participants are asked to respond yes or no to whether they would avoid the situation if they experienced the symptom presented in each item.

The questionnaire was prefaced with an information sheet, explaining the rationale, and how to complete items. It also stated that if participants would normally avoid a situation presented, they should still answer questions, by imagining their responses as if they were in the situation.

Open-ended responses were judged by two independent judges (see Appendix XVII for categories), and information on reliability and validity of the questionnaire is presented in the results section.

2.3.3.2 Hospital Anxiety and Depression Scale (HADS): (Zigmond and Snaith, 1983). The HADS is a 14 item self-report scale developed expressly to measure anxiety and depression amongst medical outpatients (Appendix VII). Total scores for each subscale are obtained by adding together responses to individual items, with the range of possible scores for each subscale of 0-21. Results are interpreted according to scoring bands, which can be found in Appendix VIII. This study used only the anxiety scale, (seven items) which measures general state anxiety experienced over the week prior to completion of the measure. The instrument was chosen as it has good psychometric properties (reliability: Cronbachs alpha=0.93) for medical patients aged 16-65 years (Zigmond and Snaith, 1983), and 65 years and above (Chaturvedi, Chandra, Channabasavanna & Beena, 1994; Johnson, Burvill, Anderson, & Jamrozik, 1995). The HADS does not include somatic symptoms of anxiety and hence is unlikely to be confounded by participants physical symptoms associated with COPD.

2.3.3.3 St Georges Respiratory Questionnaire (SGRQ): The SGRQ is a standardized self-completed questionnaire for measuring impaired health and perceived well-being (quality of life) in airways disease (Jones, Quirk & Baveystock, 1991) (Appendix IX). The original questionnaire contains 76 items, contributing to three component scores: symptoms, activity, and impact on daily life. For this study, only the 'symptoms score, containing nine items answered using a rating scale, which assess frequency and severity of symptoms associated with COPD, was used as a measure of illness severity. Responses are weighted, and together provide a percentage figure where higher percentage figures have been shown in studies to correlate with more severe physiological impairment related to respiratory disease (Jones, Quirk, Baveystock, & Littlejohns, 1992). The questionnaire has been demonstrated to be a valid measure of impaired health in

diseases of chronic airflow limitation, that is repeatable (alpha=0.91) and sensitive (Jones *et al.*, 1992).

2.3.3.4 Short Form Social Support Questionnaire (SSQ6): (Sarason *et al.*, 1987). The SSQ6 (Appendix X) is a six item version of the original 27 item SSQ (Sarason, Levine, Basham, & Sarason, 1983). It yields one quasi-structural measure (SSQ6-N; number of supports), and one global functional measure (SSQ6-S; satisfaction with support). It is a self-report measure, taking under 10 minutes to complete. For each of the six questions, participants are asked to list all the individuals known to them who provide the particular type of support described in each question. Respondents then have to rate, on a six-point scale, their level of satisfaction with this type of support. For this study, only the SSQ6-S measure was used in analysis, yielding a mean satisfaction score across all six items. The SSQ6 has high internal consistency (alpha=0.93), and good test-retest reliability. Validity is also reported to be good with superior sensitivity to other scales in a comparison study (Sarason *et al.*, 1987).

2.3.3.5 Background Information: Consisting of nine items, the Background Information Sheet (Appendix XI) included basic demographic data (age, date of birth, sex), specific diagnosis, duration of illness, medication use, number of hospital stays relating to COPD, (in total, and within the last year), and average duration of any periods spent in hospital. The information sheet was designed by the author, based on a similar one used in another study with people with breathing disorders, which was designed by a Clinical Psychologist in conjunction with an experienced Chest Physician (Schembri-Wismayer, 1995; personal communication). No formal tests of its reliability and validity were carried out.

2.4 PROCEDURE

Regional Ethics Committee approval was sought and received initially to complete the pilot study for the development of the IBPQ (Appendices XII and XIII). Permission was also given by the ethics committee to approach potential participants for the main study, and to use the HADS. Following completion of the initial investigations, and subsequent development of the IBPQ, the questionnaire was given approval, and later applications gained approval to use the SGRQ, and the SSQ6 (See Appendices XIV and XV).

2.4.1 Initial Investigation: All people who returned consent forms agreeing to take part in the study were contacted by telephone, and appointments made to interview them in their homes (although there was an option of being interviewed at the hospital, no-one chose it). At interview, the rationale was again explained, and participants completed the structured interview with the author present to help with any difficulties or questions that came up. Interviews lasted around 60 minutes.

2.4.2 Main Study: People who returned consent forms and who agreed to take part, in response to the original information letter or reminder, were contacted by telephone, and an appointment made to see them at home (again, no-one chose to be interviewed at hospital). Those people who returned the consent forms with requests for more information were also contacted by telephone, and additional information given. They were then given the option to take part or not. People who returned the form and chose not to take part, and those who did not respond to the reminder letter, were not contacted again by the author.

The author was present at all interviews, which lasted between 45 and 90 minutes. An explanation of the rationale was given, and there was time for participants to ask any questions about the study during the interview. Each of the 5 measures was presented with verbal and written instructions, and participants either completed these themselves, or, for those who had difficulty with writing, verbal responses were given to each question, and forms were completed by the author. 18 participants also agreed to complete the IBPQ a second time, 4-6 weeks after their initial interview. Retests were completed independently, sent by post with a covering letter (Appendix XVI) and a prepaid envelope. A contact number was included in the letter to ensure any questions they may regarding completion could be answered.

Section 3

RESULTS

3. RESULTS

3.1 OVERVIEW OF RESULTS SECTION

Demonstration of reliability and validity factors associated with the development of the IBPQ was completed concurrently with investigation of the core hypotheses, due to restrictions in time for completion of the project. Hence, the same participants were involved in both stages of the project. Following presentation of details of sample characteristics and scores on self-report questionnaires, investigations of the reliability and validity of the IBPQ will be presented, with examples of the types of open-ended responses elicited by the questionnaire. There will then be details of the statistical investigations of the four core hypotheses.

3.1.1. Response Rates

Details of response rates are presented in Table 2.

Table 2. Table of responses to letters inviting potential participants to take part

	Total number of letters sent (%)	Number of responses - agree to participate (% of total letters sent)	Number of responses - decline to partake (% of total letters sent)	Number of 'no' responses (% of total letters sent)
Females	32 (49.2)	**19 (29.2)**	9 (13.8)	4 (6.2)
Males	33 (50.8)	**18 (27.7)**	7 (10.8)	8 (12.3)
Total	65 (100)	**37 (56.9)**	16 (24.6)	12 (18.5)

A total of 65 letters were sent to potential participants inviting them to take part in the study, eliciting responses from 53 people (82% response rate) of whom 16 people (25% of the total sample) declined to participate. Twelve of the people approached (19%) did not respond, despite reminder letters being sent. Of the 37 people who chose to take part, 19 were female, and 18 were male.

3.1.2 Demographic Data for the sample is presented in Table 3.

Table 3. Demographic data for participants in main study

	Number	Mean age in years (SD)[a]	Mean duration of illness in years (SD)	Mean number of visits to hospital (SD)	Medication - Number of participants on:			Individual diagnoses (within COPD[g])		
					Inh[b]	Ste[c]	O_2[d]	Asthma	Emph/Bron[e]	Other[f]
Females	19	52.3 (21.8)	9.8 (17.8)	1.2 (1.8)	5	11	3	11	8	0
Males	18	66.9 (8.1)	12.2 (15.9)	0.9 (2.0)	3	12	3	5	12	1
Total	37	59.4 (17.5)	11.0 (16.7)	1.1 (1.9)	8	23	6	16	20	1

[a]standard deviation; [b]Standard inhaler medication only (e.g. ventolin); [c]Steroid medication in addition to ventolin inhaler; [d]Oxygen for a minimum of 16 hours per day, in addition to inhalers and steroid medication; [e]Emphysema &/or bronchitis; [f]Forms of COPD other than asthma, emphysema and bronchitis; [g]Chronic Obstructive Pulmonary Disease.

The mean age of participants was 59.4 years (SD=17.5; median=64 years; range=18-80 years). The mean age of females was 52.3 years (SD=21.1; median=59 years; range=18-80 years), and for males was 66.9 years (SD=8.1; median=67.5years; range=51-78 years). The mean duration of illness for the whole sample was 11 years (SD=16.7; median=7 years; range=1-80 years), and the mean number of hospital visits in the last year was 1.1 (SD=1.9; range=0-8 visits). While the whole sample used basic inhaler medication, 29 people (78%) took steroids in addition, and of these, 6 people (16%) used oxygen for a minimum of 16 hours per day as well. Each participant fulfilled the criteria for COPD, and within this diagnostic category, 16 people (43%), 11 of them females, had asthma, 20 (54%) had bronchitis or emphysema, and one person (3%) had lung disease related to asbestos exposure.

3.1.3 Self Report Questionnaires The data from the self-report questionnaires is presented in Table 4.

Table 4: Mean scores on HADS, SGRQ and SSSQ6.

	Mean HADS[c] (SD)[a]	Number of scores above cut-off[b] (%)	Mean score on SGRQ[d] (SD)	Mean score on SSQ6[e] (SD)
Female (n=19)	8.5 (3.7)	14 (73.7)	71.1 (21.2)	4.7 (1.4)
Male (n=18)	7.1 (4.2)	7 (38.9)	71.8 (19.4)	5.0 (1.2)
Total (n=37)	7.8 (4.0)	21 (56.8)	71.4 (20.0)	4.8 (1.3)

[a]standard deviation; [b]cut-off for borderline clinical significance >7 (Snaith and Zigmond, 1994); [c]Hospital Anxiety and Depression Scale; [d]St. George's Respiratory Questionnaire; [e]Short Form Social Support Questionnaire-6

Hospital Anxiety and Depression Scale (HADS) scores for the whole sample had a mean of 7.8 (SD=4.0; range=0-15). Of these, 21 participants (57%) scored above 7, the cut-off for borderline anxiety (Snaith and Zigmond, 1994), this figure comprising 13 female participants (67%).

St. George's Respiratory Questionnaire (SGRQ) scores for the whole sample had a mean of 71.4 (SD=20.0; range=15-98).

Short-Form Social Support Questionnaire-6 (SSQ6) scores for the whole sample had a mean of 4.8 (SD=1.3; range=2-6).

3.2 THE INTERPRETATION OF BREATHING PROBLEMS QUESTIONNAIRE (IBPQ)

The 'Interpretation of Breathing Problems Questionniare' (IBPQ) was designed to elicit a range of cognitions relating to symptoms of COPD. Before the psychometric properties of the questionnaire are described, a brief descriptive summary of the range of cognitions elicited will be presented, to give the reader an example of the type of responses that were given to open-ended questions.

Open-ended responses were categorised into non-catastrophic, moderately catastrophic, and severely catastrophic thoughts (see Appendix XVII for defining categories). In total, 302 (58%) of the 518 responses were classified as non-catastrophic, 132 (25%) were classified as moderately catastrophic, and 83 (16%) as severely catastrophic (one response was missing). Table 5 gives four examples of each type of response, while a more inclusive table of the range of responses in each category is given in Appendix XVIII.

Table 5: Examples of types of open-ended responses according to category of severity

Category of response	*Examples of responses*
Non-catastrophic	'I'm OK because the Dr. is here, so even if I get worse I'll be OK' 'I'll cope because my husband is always here (*at home*) with me' 'Embarrased (*at wheezing in company*), but I'll take my ventolin and I'll be fine' 'I'll be alright after a rest'
Moderately catastrophic	'I'm going to have a problem breathing' 'I won't be able to catch my breath' 'I must slow down and take my ventolin or it (*my breathing*) will get worse' 'I'll get dizzy and breathless'
Severely catastrophic	'I must get out (*of the smokey pub*) - very anxious - I'll collapse' 'I'll stop breathing and get brain damage' 'I haven't got much time before I collapse' 'It (*wheezing*) will get worse - I won't be able to breathe, and I wouldn't have any oxygen with me'

Establishment of the psychometric properties of Interpretation of Breathing Problems Questionnaire (IBPQ)

3.2.1 Safety ratings for 14 different situations: Is there a significant difference between ratings of safety, given the seven 'safe' and seven 'unsafe' situations used in the IBPQ?:

Twenty people (See Method, Section 2.3.2 (iii)) were asked to rate 14 different situations that had been described as 'more safe' and 'less safe' during the initial interviews, on an ordinal scale of 1 (safe) to 4 (unsafe). Table 6 summarises the responses.

Table 6: Ratings of how safe or unsafe 14 different situations were.

Situations	Mean (SD)[a]	Friedmans 2-way Anova		
		d.f.[b]	c^{2c}	*p*
Safe	1.29 (0.51)	6	8.4	0.21
Unsafe	3.04 (0.84)	6	11.9	0.07
All 14	2.18 (1.14)	13	171.9	0.0001

[a]standard deviation; [b]degrees of freedom; [c]Chi-squared

The mean score for 'safe' situational variables was 1.29 (SD=0.51), and for 'unsafe' was 3.04 (SD=0.84). Ratings were made on an ordinal scale, and a Kolgomorov-Smirnoff Goodness of Fit Test indicated that the data was not normally distributed. For these reasons, a Friedmans Two-Way Analysis of Variance was used in analysis of the data. This revealed the presence of a significant difference (Chi-Square=171.9; d.f.=13; $p<.0001$) in ratings given to the 14 situations. When the 14 variables were split into the seven 'safe' situations and the seven 'unsafe' situations, two further Friedmans Two-Way Analyses of Variance found no significant differences between ratings given to the 14 situations, (**safe:** Chi-Square=8.4; d.f.,6; non-significant; **unsafe:** Chi-Square=11.9; d.f.=6; non-significant).

3.2.2 Inter-rater reliability for open-ended responses (cognitions):

Open-ended responses to each of the 14 items in the IBPQ provided a range of cognitions from each of the 37 participants. All responses (518), were rated by two independent judges, who allocated them into one of three categories: non-catastrophic, moderately catastrophic, and severely catastrophic. Rating categories are defined in Appendix XVII. A summary of the correlation of these ratings is presented in Table 7.

Table 7: Summary of correlation of ratings by judges 1 and 2

		Judge 2		
		Non-cat.[a]	Mod. cat.[b]	Sev.cat[c]
Judge 1	Non-cat.	**285**	17	0
	Mod. cat	7	**100**	25
	Sev.cat	1	2	**80**

Note: Figures in bold represent responses rated same by both judges;
[a]non-catastrophic rating; [b]moderately catastrophic rating;
[c]severely catastrophic rating

Four hundred and sixty-five (90%) of the 518 responses were rated the same by both judges, with a total of 285 non catastrophic, 100 moderately catastrophic, and 80 severely catastrophic thought ratings. There was one missing response due to one participant being unable to answer one question. Judge 2 rated 42 responses in one category as more catastrophic than they were rated by judge 1, and only eight responses were rated more catastrophic by judge 1. Overall reliability was calculated using Cohens Kappa, eliciting a value of 0.83 (standard error=.02). This indicated a 'substantial' to 'almost perfect' agreement between judges, (95% confidence interval, (0.79, 0.870)) (Landis and Koch, 1977). One participant (number 34) responded to each of the 14 open-ended questions with exactly the same response, ('I'd have difficulty breathing'), which was rated by both judges as moderately catastrophic. The Kappa value was

therefore recalculated without this data, as a series of identical responses might skew results, giving a higher inter-rater reliability value than would be obtained if there were a variety of responses from each participant. The recalculated Cohens Kappa value was 0.82 (Standard error=.23), again, indicating substantial agreement (95% confidence interval (0.78, 0.86)).

3.2.3 Test-Retest Reliability: Eighteen participants completed the IBPQ a second time, four to six weeks after the original assessment session. Test-Retest Reliability was calculated for each of the 14 questions, for open-ended responses, ratings of anxiety, ratings of belief in becoming ill, and ratings of belief in dying.

Open-ended responses: Correlation coefficients were calculated for each of the 14 questions, and the percentage of responses in the same category at the second testing was also calculated. A Kendall-Tau test was chosen as a Kolgomorov-Smirnoff Goodness of Fit Test indicated that the distribution of scores of catastrophic thoughts was not normal, and the range of categories was only small (1-3). A summary of correlation coefficients for open-ended responses is presented in Table 8.

Table 8: Test-retest reliability of open-ended responses - Correlation coefficients, significance, and number of items scored identically at first and second testing.

	Correlation Coefficient	*Number of participants rating item same at 2nd testing (%) (n=18)*
Safe Situations		
Friends house - chest tight	.66**	16 (89)
Stairs/home - hard to breathe	.65**	14 (78)
Hospital - tired/exhausted	.47^{ns}	14 (78)
With Physio - chest congested	.85****	17 (94)
Home with friend - wheeze	.85****	16 (89)
GP surgery - cough heavily	.79***	14 (78)
Garden/friend - short of breath	.55*	14 (78)
Unsafe Situations		
Smokey Pub - chest tight	.78****	13 (72)
Stairs at shop - hard to breathe	.70**	12 (67)
Crowd/town - tired/exhausted	.82****	14 (78)
Drive-m/way - chest congested	.72***	12 (67)
Crowded bus - wheeze	.87****	15 (83)
Supermarket - cough heavily	.84****	13 (72)
Long walk - short of breath	1.00****	18 (100)

*$p<.05$; **$p<.01$; ***$p<.001$; ****$p<.0001$; ^{ns}non-significant

Correlation coefficients ranged from .47 - 1.00, with all correlations being significant at a level of $p<.01$ except for two items (In the garden with a friend - short of breath; At hospital - tired and exhausted), which were significant at $p<.05$, and non-significant at $p=.051$, respectively. For the whole group, the mean percentage of items rated the same on test-retest for each question was 80% (SD=9.46; range=67 -100%).

Ratings of anxiety, belief in becoming ill, and belief in dying: Due to the small number of participants who took part in the retest condition (n=18), it was decided to use a non-parametric statistical test to assess for significant differences between ratings over time, despite the indication from a Kolgomorov-Smirnoff Goodness of Fit test that there was no evidence to suggest that the data was not normally distributed. A Wilcoxon Matched Pairs Signed-Ranks

test was used to analyse differences in test-retest ratings of anxiety; belief in becoming ill; and belief in dying; for each of the 14 questions in the IBPQ. A table of results for individual items on the questionnaire can be found in Appendix XIX. Table 9 summarises these results.

Table 9: Test-retest reliability data for anxiety scores, belief in becoming ill, and belief in dying, in the seven 'safe' and seven 'unsafe' situations.

	Range of z scores	Range of significance levels	Number of items with significant differences at retest (%)
7 'safe' items			
Anxiety ratings	-2.58 - -0.10	0.01 - 0.92	1 (14)
Belief in becoming ill	-2.19 - 0.00	0.03 - 1.00	1 (14)
Belief in dying	-1.35 - 0.00	0.18 - 1.00	0 (0)
7 'unsafe' items			
Anxiety ratings	-2.10 - -0.35	0.04 - 0.72	2 (29)
Belief in becoming ill	-1.78 - -0.18	0.08 - 0.86	0 (0)
Belief in dying	-1.48 - -0.18	0.14 - 0.86	0 (0)

Differences in anxiety ratings for all but three questions were non-significant. The three questions for which the Wilcoxons analysis indicated significant differences in test-retest ratings were: Going up the stairs in a shopping centre and finding it hard to breathe; Being in a crowd in town and becoming tired and exhausted; Being round a friends house and your chest becoming tight. Z-scores for these responses were -2.10, -2.04 and -2.58 respectively, and all were significant at $p<.05$.

Belief in becoming ill ratings revealed no significant differences between test and retest for all but one item (You are at the hospital and begin to feel tired and exhausted; $z = -2.19$; $p<.05$), and *analysis of belief in dying* ratings revealed no significant differences between responses on the initial and retest situations.

3.2.4 Internal Consistency: Cronbachs Alpha was calculated to determine the homogeneity of the 14 items used to measure severity of catastrophic thoughts on the IBPQ. A summary of Alpha values ('if each item were deleted from the questionnaire') is presented in Table 10.

Table 10: Internal Consistency - Alpha values for IBPQ if each item were deleted from the questionnaire.

Cronbach's alpha for whole scale = .90	
	Alpha if item deleted
'Safe' Situations	
Friends house - chest tight	.90
Stairs/home - hard to breathe	.90
Hospital - tired/exhausted	.91
With Physio. - chest congested	.90
Home with friend - wheeze	.89
GP surgery - cough heavily	.90
Garden/friend - short of breath	.90
'Unsafe' Situations	
Smokey Pub - chest tight	.91
Stairs at shop - hard to breathe	.89
Crowd/town - tired/exhausted	.89
Drive-m/way - chest congested	.89
Crowded bus - wheeze	.89
Supermarket - cough heavily	.90
Long walk - short of breath	.89

The results of the analysis show that internal consistency of the scale is extremely high with an overall Cronbach's alpha value of .90. When items were analysed individually, there were none that would have significantly altered the overall alpha value if removed.

3.2.5 Construct Validity: Anxiety ratings for each of the 14 questions were correlated with the HADS score for each participant. However, the responses of one participant (number 34) were thought likely to skew correlation coefficients as a result of responses being identical, with consistently high ratings of anxiety, belief in becoming ill, and belief in dying, particularly for

the 'safe' situations. This is indicated by Figures 1-3 in Appendix XX, which suggest that this participants' scores are significant outliers when compared to the scores obtained on the measures by the rest of the sample.

For this reason, correlations were carried out first for all 37 participants, and then recalculated for 36 participants, without the data from this participant. A Pearsons correlation was used as a Kolgomorov-Smirnoff Goodness of Fit Test indicated that there was no evidence to suggest that HADS scores and anxiety ratings were not both normally distributed. A summary of the results of these analyses is presented in Table 11, and a table of individual correlations and significance levels can be found in Appendix XXI.

Table 11: Correlations of anxiety ratings for each question, with individual HADS scores, for (i) all 37 participants, and (ii) without outliers scores.

			Range of Correlation Coefficients	Mean correlation (SD)[a]	Number of $p<0.01$ values (%)	Number of non-sig. values (%)
(i) All participants (n=37)	HADS[b] score correlated with: -	- anxiety ratings - **safe situations**	.17 - .39	.26 (.07)	1 (14)	3 (43)
		- anxiety ratings- **unsafe situations**	.16 - .52	.41 (.11)	6 (86)	1 (14)
(ii) Excluding outlier (n=36)	HADS score correlated with: -	- anxiety ratings - **safe situations**	.32 - .64	.44 (.10)	5 (71)	0 (0)
		- anxiety ratings- **unsafe situations**	.22 - .62	.50 (.12)	6 (86)	1 (14)

[a]standard deviation, [b]Hospital Anxiety and Depression Scale

(i) Correlations with data from all 37 participants: Correlation coefficients ranged from .16 to .52 for the 14 items. For 'safe' situation anxiety ratings, four items were significantly correlated with HADS scores at a $p<.05$ level, with non-significant p-values for the other 3 items of .11-.16. A significance level of $p<.01$ was obtained for all 'unsafe' situation anxiety ratings except

for one: Driving down a motorway and your chest begins to become congested, which was non-significant ($p<.18$).

(ii) Correlations with data excluding the outlier: When the outlying scores were excluded from the analysis, correlation coefficients ranged from .22 to .64 for all 14 anxiety ratings with the HADS scores. Significance levels were all at $p<.05$ for all items, again with the exception of the item outlined in the previous analysis, which remained non-significant. In the 'safe' situations, when data for participant 34 was omitted, five anxiety ratings became significantly correlated with HADS scores at the $p<.01$ level, and 2 at $p<.05$.

As a further measure of construct validity, the severity of catastrophization in responses to open-ended questions was correlated with ratings of anxiety on the IBPQ. The results of these correlations are shown in Table 12. A table of individual correlations for each item is presented in Appendix XXII.

Table 12: Construct Validity - Correlations of open-ended responses with anxiety ratings on the IBPQ.

Open-ended responses correlated with anxiety	Range - correlation coefficients	Mean correlation (SD)[a]	Number of $p<.01$ values (%)
	.32 - .81	.62 (0.12)	13 (93)

[a]standard deviation

Correlation coefficients ranged from .32 - .81, and 13 of the 14 correlations were significant at $p<.01$, the other correlation being significant at $p<.05$.

3.2.6. Concurrent Validity. Ratings of belief in becoming ill, and belief in dying were correlated with open-ended responses, to see if more severe catastrophization responses, reflecting thoughts about becoming more ill or dying for each item on the IBPQ, were accompanied by more severe specific ratings of these constructs on the questionaire. Due to open-ended responses being on an ordinal scale, and not being normally distributed, Spearmans Correlation coefficients were calculated and are shown in Table 13. A table of all correlation coefficients and significance levels for individual items is presented in Appendix XXIII.

Table 13: Concurrent Validity: Correlations of open-ended responses with ratings of belief in becoming ill; and belief in dying, for all participants.

Open-ended responses correl. with:	Range - correlation coefficients	Mean correlation (SD)[a]	Number of $p<.01$ values (%)
- belief/illness	.33 - .84	.58 (0.14)	13 (93)
- belief/dying	.33 - .76	.55 (0.12)	12 (86)

[a] standard deviation

Correlation coefficients ranged from .33 to .84 when open-ended responses were correlated with ratings of belief in becoming ill, and belief in dying, and all correlations were significant at a level of $p<.05$, with an overall 90% of correlations being significant at a level of $p<.01$.

The statistical analyses presented in the previous section indicate that the IBPQ has favourable reliability and validity. However, in the light of the data presented, the results of the analyses of the following hypotheses should be viewed with caution, as further investigation is needed before a conclusive statement can be made regarding exact reliability and validity of individual items on the IBPQ, and the questionnaire as a whole.

3.3 INVESTIGATION OF HYPOTHESES

3.3.1. Hypothesis 1: A high prevalence of clinically significant anxiety will be found in a sample of COPD patients.

A summary of mean total HADS scores, and the number of participants scoring in each category of severity is presented in Table 14.

Table 14: Summary of HADS scores for participants, with ranges of clinical significance.

	Mean HADS[b] (SD)[a]	HADS severity categories: (number & %)			Total above cut-off score[c]
		Mild (8-10)	Moderate (11-14)	Severe (15-21)	
Female (n=19)	8.5 (3.7)	9 (47.4)	5 (26.3)	0 (0)	14 (73.7)
Male (n=18)	7.1 (4.2)	2 (11.1)	4 (22.2)	1 (5.6)	7 (38.9)
Total (n=37)	7.8 (4.0)	11 (29.7)	9 (24.3)	1 (2.7)	21 (56.8)

[a]standard deviation; [b]Hospital Anxiety and Depression Scale; [c]cut-off >7 (Zigmond and Snaith, 1994)

The mean HADS score for the whole sample was 7.8 (SD=4.0; range=0-15). Of these, 21 participants (57%) scored above the cut-off of >6 for clinically significant anxiety, 67% of this figure were female. There was one score in the severe anxiety range (15-21), and 9 participants (24%) scored in the moderate range. The authors of the scale (Zigmond and Snaith, 1983) state that for research purposes, it may be useful to include only data from the upper end of the mild (borderline) range to eliminate the likelihood of a high proportion of false positive diagnoses. Without the data from the 11 participants with scores of 8-10, 10 participants (27% of the sample) remained within the range of moderate to severe (probable) clinical significance for anxiety.

3.3.2 Hypothesis 2: The presence of more severe catastrophic thoughts will be related to higher levels of (a) generalised anxiety (HADS anxiety) and (b) anxiety ratings on the IBPQ.

3.3.2(a) Mean total catastrophic thought ratings were correlated with HADS anxiety scores for each participant. A Spearmans Correlational analysis was used as a Kolgomorov-Smirnoff Goodness of Fit test indicated that the distribution of means of catastrophic thought ratings was not normal. Correlations were also carried out for catastrophic thought ratings to symptoms in 'safe' and 'unsafe' situations separately. A summary of these correlations is presented in Table 15.

Table 15: Correlations of open-ended responses (severity of catastrophic thought ratings) with HADS scores

Correlations of severity of catastrophic thoughts with HADS[a] scores for:	Correlation coefficient
- all 14 items	.49***
- 'safe situation items	.21[ns]
- 'unsafe' situation items	.54****

***p<.001; ****p<.0001; [ns]non-significant
[a]Hospital Anxiety and Depression Scale

A correlation coefficient of .49 (p<.001) was obtained for the correlation of catastrophic thoughts with HADS scores. When the correlation was repeated using ratings of catastrophic thoughts from 'safe' and 'unsafe' situations separately, coefficients of .21 and 0.54 respectively, were obtained, the former being non-significant, and the latter being highly significant at p<.0001. The results of the correlation of 'all catastrophic thoughts' with HADS scores supports the hypothesis that more severe catastrophic thoughts are related to higher levels of

generalised anxiety (HADS anxiety). This relationship is also true for catastrophic thoughts to symptoms made in 'unsafe' situations, but not for thoughts relating to 'safe' situations.

3.3.2(b) The mean total of open-ended responses (catastrophic thought ratings) was correlated with a single mean of the anxiety ratings for all 14 items on the IBPQ for each participant. As before, a Spearmans Correlation was calculated due to the distribution of open-ended responses not being normal. Correlation coefficients were also calculated for anxiety ratings with catastrophization scores, for the seven 'safe' and the seven 'unsafe' situations separately. The results of these analyses are presented in Table 16.

Table 16: Correlations of catastrophic thoughts with anxiety ratings on the IBPQ.

Correlations of severity of catastrophic thoughts with anxiety ratings on IBPQ for:	Correlation coefficient
- all 14 items	.80****
- 'safe situation items	.67****
- 'unsafe' situation items	.73****

****p<.0001;
IBPQ = Interpretation of Breathing Problems Questionnaire

When open-ended responses (severity of catastrophic thoughts) were correlated with anxiety ratings, correlation coefficients of .8, .7 and .7 were obtained for all 14 items, 'safe', and 'unsafe' situations respectively. All correlations were highly significant at the p<.0001 level, supporting the hypothesis that more severe catastrophic thoughts are related to higher anxiety ratings on the IBPQ.

3.3.3 Hypothesis 3: In situations that are perceived as being more threatening ('unsafe'), participants are more likely to, (a) have more severe catastrophic thoughts; and (b) report higher levels of anxiety in response to symptoms, than in situations perceived as less threatening.

3.3.3a The means of open-ended response ratings to symptoms presented in 'safe' and 'unsafe' situations were calculated, and compared using a Wilcoxon Matched-Pairs Signed-Ranks test, (one-tailed), as the data was shown not to be normally distributed using a Kolgomorov-Smirnoff Goodness of Fit test. The means of catastrophic thought ratings in 'safe' and 'unsafe' situations were 1.27 (SD=.63) and 1.88 (SD=.38) respectively, and a highly significant difference was found between catastrophic responses in the two situations ($z = -4.88$, $p<.0001$), thus supporting the hypothesis that more severe catastrophic thoughts will be experienced in threatening situations than in 'safer' ones.

3.3.3b Due to the normal distribution of scores (indicated by a Kolgomorov-Smirnoff Goodness of Fit test), a t-test for paired samples was used to compare ratings of anxiety made in 'safe' and 'unsafe' situations. The means of anxiety ratings in 'safe' and 'unsafe' situations were 3.12 (SD=1.79) and 5.18 (SD=2.30) respectively. A t-value of 9.78 ($p<.0001$; d.f.=36) was obtained, again, indicating a highly significant difference between ratings of anxiety in each of these conditions, and thus supporting the hypothesis that more severe catastrophic thoughts will be experienced in threatening situations than in 'safer' ones.

3.3.4 Hypothesis 4: Severity of catastrophic thoughts (open-ended responses) will predict more of the variance in anxiety than other variables associated with anxiety, including disease severity, duration of COPD, age, and satisfaction with social support.

Three stepwise multiple regressions were carried out to ascertain the factors that would account for a proportion of the variability in the dependent variable of 'anxiety'. In all three regression analyses, the dependent variable was anxiety, assessed using the HADS. Independent variables entered into the regression were age, duration of illness (years), satisfaction with social support (measured on the SSQ6), severity of illness (measured on the SGRQ), and, in the first multiple regression, total severity of catastrophic thought ratings, in the second, severity of catastrophic thought ratings in 'safe' situations, and in the third, severity of catastrophic thought ratings in 'unsafe' situations. The results of these regression analyses is presented in Table 17.

Table 17: Summary of the three multiple regressions showing independent variables that explain significant amounts of the variance in the HADS score

#	Dependent Variable	Independent variables entered into stepwise regression equation that were significant	B	T	R^2	d.f.	F
(i)	**HADS anx.**	*1. Social support satisfaction*	-1.34	-2.94**	0.39	2,34	10.99***
		2. All catastrophic thoughts	2.81	2.18*			
(ii)	**HADS anx.**	*1. Social support satisfaction*	-1.73	-3.94***	0.31	1,35	15.55***
(iii)	**HADS anx.**	*1. Catastrophic thoughts - unsafe situations*	2.43	2.56*	0.42	2,34	12.27***
		2. Social support satisfaction	-1.49	-2.46*			

*p<.05; **p<.01; ***p<.001

- Where all independent variables put forward for entry into each of the 3 stepwise regressions are: Age; Duration of illness; Satisfaction with social support; Illness severity and:

(i) All catastrophic thoughts
(ii) Catastrophic thoughts in 'safe' situations
(iii) Catastrophic thoughts in 'unsafe situations'

The multiple regressions provided a summary of the variables that explained a significant proportion of the variability of HADS anxiety. In all three regressions, age, duration of illness, and severity of illness, did not add significantly to an explanation of the variance in the HADS anxiety score.

(i) In the first analysis where the mean of 'all catastrophic thoughts' was entered as one of the independent variables, social support was shown to be most strongly related to HADS anxiety, with a negative T value of -2.94 ($p<.006$). Catastrophic thoughts were also shown to relate significantly to the HADS score, although less strongly than social support (T=2.18; $p<.04$). Together, these 2 variables explained 39% of the variance of HADS anxiety, ($R^2=0.39$; d.f.=2,34; $p<.0002$).

(ii) In the second analysis where catastrophic thoughts relating to symptoms in 'safe' situations were included as one of the five independent variables, only social support was significant in explaining the variance of the HADS score, with a T-value of -1.73 ($p<.0004$), accounting for 31% of the variance ($R^2=0.31$; F=15.55; d.f.=1,35; $p<.0004$).

(iii) The final analysis included catastrophic thoughts relating to symptoms in 'unsafe' situations, which was the most strongly related independent variable to HADS anxiety (T=2.56; $p<.015$). Social support explained a slightly lesser amount of the variance (T = -2.49; $p<.019$), and together with catastrophic thoughts, explained around 42% of the variance of the HADS score ($R^2=0.42$; F=12.27; d.f.=2,34; $p<.0001$).

On the above analyses, the positive B-values of 2.81 and 2.43 for the catastrophic thought variables on analyses (i) and (iii), indicate a strong positive relationship between HADS anxiety and severity of catastrophic thoughts, with a higher HADS anxiety score correlating with more severe catastrophic thoughts. The negative B-values on all three analyses, indicate a strong negative relationship between HADS anxiety and satisfaction with social support, where higher HADS anxiety scores were strongly related to less satisfaction with social support.

The results of these regressions support the hypothesis that catastrophic thoughts are more predictive of anxiety, (in this case generalised anxiety assessed on the HADS), than severity and duration of illness, and age. However, contrary to the hypothesis, satisfaction with social support also explained a significant amount of the variance in the HADS score, particularly when 'catastrophic thoughts relating to symptoms experienced in 'safe' situations' was entered as an independent variable.

Three further multiple regressions were carried out, with the mean anxiety rating scores from the IBPQ as the dependent variable. Independent variables remained the same as those in the first set of regression analyses, with open-ended responses (catastrophic thoughts) in relation to (i) all, (ii) safe, and (iii) unsafe conditions being the only independent variable to change in each of the 3 analyses. Table 18 summarises the results of these analyses.

Table 18: Summary of multiple regressions showing independent variables that explain a significant amount of the variance in mean anxiety rating score on the IBPQ

#	Dependent Variable	Independent variables entered into stepwise regression equation that were significant	B	T	R^2	d.f.	F
(i)	**Anxiety ratings on IBPQ**	*1. All catastrophic thoughts*	3.18	6.39****	0.54	1,35	40.9****
(ii)	**Anxiety ratings on IBPQ**	*1. Catastrophic thoughts - - safe situations* *2. Social support satisfaction*	3.02 -0.42	4.64**** -2.16*	0.47	2,34	14.8****
(iii)	**Anxiety ratings on IBPQ**	*1. Catastrophic thoughts - unsafe situations*	2.11	5.44****	0.46	1,35	29.5****

*p<.05; ****p<.0001

- Where all independent variables put forward for entry into each of the 3 stepwise regressions are: duration of illness; satisfaction with social support; illness severity and:

(i) all catastrophic thoughts
(ii) catastrophic thoughts in 'safe' situations
(iii) catastrophic thoughts in 'unsafe situations'

As in the multiple regression analyses in section 3.3.4a, age, duration of illness, and severity of illness, did not add significantly to the explanation of variance in anxiety ratings after more significant variables had been entered into the equation.

(i) In the first analysis, severity of 'catastrophic thoughts in all 14 situations' was the only independent variable that accounted for variance in the anxiety score on the IBPQ, with a T value of 6.39 (p<.0001). Catastrophic thoughts accounted for 54% of the anxiety rating variance (R^2=0.54; F=40.89; d.f.=1,35) at a significance level of p=.0001. Social support did not contribute to an explanation of the variance.

(ii) In second analysis, the mean of 'severity of catastrophic thoughts relating to symptoms in safe situations' was the independent variable that most significantly explained the variance of anxiety ratings on the IBPQ, with a T-value of 4.64 (p<.0001). Satisfaction with social support

was also related, but less significantly than catastrophic thoughts, (T = -2.16; $p<.04$). Together, these variables accounted for 47% of the variance ($R^2=0.47$; F=14.81; d.f.=2,34) at a significance level of $p<.0001$.

(iii) In the final analysis, 'catastrophic thoughts to symptoms in 'unsafe' situations' was the only independent variable related to anxiety ratings on the IBPQ (T=5.44; $p<.0001$), explaining around 46% of the variance of the anxiety score ($R^2=0.46$; F=29.54; d.f.=1,35; $p<.0001$).

As before, the positive B-values of 3.18, 3.02, and 2.11 on analyses (i), (ii), and (iii) respectively, indicated a strong positive relationship between catastrophic thoughts and anxiety ratings, with more severe catastrophic thoughts correlating with higher anxiety scores on the IBPQ. The negative B-value on the second analysis indicates a negative relationship between satisfaction with social support and anxiety.

The results of these regressions also support the hypothesis that catastrophic thoughts are more predictive of anxiety, (in this case, anxiety ratings made to the experience of a range of symptoms in a range of situations on the IBPQ), than disease severity, age, and duration of illness. As before, satisfaction with social support also explained a significant amount of the variance in the anxiety score, when 'catastrophic thoughts in response to safe situations' was entered as an independent variable, but was not relevant in the other two regressions. Cognitions were more strongly predictive of anxiety ratings measured on the IBPQ than to HADS anxiety.

3.4 Additional analysis: Although there was not a direct hypothesis relating to participants' 'avoidance' scores on the IBPQ, it was felt that it would be of interest to assess whether there was a significant difference between avoidance of situations in 'safe' and 'unsafe' situations. In this analysis, a non-parametric test was considered most appropriate as there were only two possible responses to be taken into account (yes/no), hence a Wilcoxon Matched-Pairs signed-ranks test was used to analyse the data. The mean of scores for the seven 'safe' situations (mean number of 'safe' situations avoided) was 1.03 (SD=1.72; range=0-7), and for 'unsafe' situations, the mean number of situations avoided was 3.54 (SD=2.24; range=0-7). A highly significant difference was found between avoidance of 'safe' and 'unsafe' situations, with a z-score of -4.94 ($p<.0001$), indicating that there was significantly more avoidance of 'unsafe' situations than of 'safe'.

Section 4

DISCUSSION

4. DISCUSSION

Overview of Discussion There were two main aims of this study. The first was to develop a questionnaire that could be used to elicit cognitions and ratings of predicted anxiety, related to a variety of symptoms associated with COPD in a range of situations. The second aim was to investigate a number of hypotheses about the relationship of cognitions, in particular catastrophic thoughts, to anxiety. This was done using the new questionnaire (the IBPQ) in addition to three other standardised questionnaires and a background information sheet. Investigations of the reliability and validity of the IBPQ will be presented first, with discussion about how the psychometric properties of the questionnaire can be improved in the future. The second section of the discussion will present a summary of the results from the testing of the hypotheses, which will be followed by a discussion of methodological considerations. Finally, interpretation of the main research findings, with implications for clinical practice and future research will be discussed in the light of the results of this study.

4.1 SUMMARY OF RESEARCH FINDINGS

4.1.1 Psychometric Properties of the IBPQ:

The range of situations described in the 14 items on the IBPQ were rated for safety, and a significant difference in safety was found between seven of the items rated as 'more safe' and seven items rated as 'more unsafe'. The effect of situation on cognitions and anxiety was therefore included in the analyses of hypotheses.

4.1.1.1 Reliability: The analyses carried out indicate that the reliability of the IBPQ was good. *Inter-rater reliability* for the IBPQ was high, with 90% agreement (Kappa = 0.83) between the two independent judges for categorising open-ended responses according to their level of severity. *Internal consistency* of the IBPQ was extremely high (Cronbach's alpha=0.90) when responses to each of the 14 open-ended questions for each participant were assessed for homogeneity.

Test-retest reliability was high for most of the open-ended items, with significant correlations for five of the seven items incorporating 'safe' situations, and for all items incorporating 'unsafe' situations. Despite the non-significant correlations of two items, 14 (78%) of the 18 participants who completed the retest condition actually rated them the same as they had done in the original condition. However, the Kendalls-Tau analysis which was chosen to assess the correlations takes into account the degree of variance within the total responses made to each item, and it is likely that the generally lower significance of items in the 'safe' condition is attributable to the fact that most responses to these seven items were non-catastrophic. This resulted in less variance in responses as a whole. Test-retest reliability for ratings of anxiety, belief in becoming ill, and belief in dying, were generally high. On the items that showed differences in test-retest analysis, ratings and open-ended responses were generally higher at the second testing. This may have been due, in part, to the psychology trainee not being present in this condition, whereas she was present throughout all initial testing. Participants may have felt more confident in their ability to cope with the situations presented when in the presence of another person. Inclusion of more participants in the retest condition might also have increased the possibility of a significant finding for test-retest reliability.

4.1.1.2 Validity: *Construct validity* was assessed by correlating anxiety ratings on the IBPQ with HADS anxiety scores. When the outlying scores of one participant were excluded from the data sample, all but one (which was non-significant) of the correlations were significant at $p<.05$. Ratings of anxiety were also correlated with open-ended responses, as a further measure of construct validity, with all but one correlation ($p<.05$) significant at $p<.01$. *Concurrent validity* was assessed by correlating open-ended responses (severity of catastrophic thought) with belief in becoming ill and belief in dying. All correlations were significant at $p<0.05$, which further supports the validity of participants' responses to questions designed to elicit cognitions.

It can be concluded from the analyses carried out, that the IBPQ has good reliability and validity as a measure of catastrophic cognitions, and as a measure of anxiety associated with those cognitions. Test-retest reliability was generally high, but may have been affected by the differences in conditions between the initial and second testing. Reliability may also have been further enhanced by inclusion of more participants in the retest condition. The questionnaire was effective in eliciting cognitions from participants, but for some people, further explanation of how to respond to open-ended questions was required before they were able to. Also, some participants spontaneously reported catastrophic cognitions in conversation, e.g. 'I never go out because I know I'd panic on my own', but their responses on the IBPQ did not reflect this severity of catastrophization. It may be that the items on the questionnaire were not appropriate stimuli to elicit all catastrophic thoughts, and for these people, a structured interview may elicit cognitions more readily. Further assessment is needed to ascertain whether elimination of items which were less significantly reliable or valid from the questionnaire would increase the overall psychometric properties of the IBPQ.

4.1.2 Summary of Investigations of Hypotheses: Data on 37 out-patients with COPD highlighted a high prevalence of clinically significant anxiety. Using the HADS, more than half the sample were identified as suffering from mild to moderate anxiety, and even with the exclusion of data from participants who scored less than 11 (lower end of the moderate range), 10 people (27% of the sample) had anxiety scores within the moderate (probable) anxiety range. Surveys of the general population suggest a prevalence rate of around 10% for such anxiety problems (Weissman & Merikangas, 1986). The figure obtained was comparable to that reported by Yellowlees *et al.* (1987) of 24%, and Porzelius *et al.* (1992) of 37%, but was much higher than the figure of 9% reported by van Peski Oosterbaan *et al.* (1996). In comparison with studies of anxiety in other medical populations which also used the HADS, the total figure (including scores in the 'mild' range) obtained in the current study is slightly higher. Chandarana, Eals, Steingart, and Bellamy (1987) reported that 21% of their sample of patients with rheumatoid arthritis scored above the HADS cut-off of 8/9, with 19% of their sample scoring in the moderate-severe range of anxiety. Another study by Ford, Lewis and Fallowfield (1995) reported that 26% of their sample of newly referred patients with cancer scored above the cut-off for anxiety on the HADS.

More severe catastrophic thoughts were significantly correlated with higher levels of both generalized anxiety (measured on the HADS scale), and situation-specific anxiety ratings on the IBPQ. For both measures of anxiety, this relationship was stronger for catastrophic thoughts in relation to symptoms experienced in 'unsafe' situations, than in 'safe', which was not significantly correlated with HADS anxiety. Significantly more avoidance was found for 'unsafe' than for 'safe' situations amongst participants in this study.

Analysis of open-ended responses showed that catastrophic thoughts were significantly more severe in response to COPD-related symptoms presented in 'unsafe' situations than in 'safe', indicating that situational variables may act as moderators for catastrophic cognitions. Anxiety ratings on the IBPQ were also significantly higher in 'unsafe' situations.

The results of the multiple regression analyses indicate that 'catastrophic thoughts' explained a significant amount of the variance in both generalized anxiety as measured on the HADS, and in anxiety ratings related to symptoms in a range of specific situations, measured on the IBPQ. Age, and severity and duration of illness, did not contribute significantly to either measure of anxiety. Social support was also important, explaining more of the variance in generalized (HADS) anxiety than cognitions when 'all catastrophic thoughts' was entered into the regression, and being the only significant contributer to HADS anxiety scores when 'catastrophic thoughts in relation to 'safe' situations' was entered. However, social support was less important in predicting anxiety than severity of catastrophic thoughts in all three of the analyses performed when anxiety ratings on the IBPQ was entered as the dependent variable. These results support the hypothesis that catastrophic cognitions are a significant predictor of anxiety, both generalized and more specific.

In summary, all the hypotheses appear to have been upheld. A high prevalence of anxiety was found, which was higher than those reported in recent studies with people with COPD, and studies with patients with other chronic medical conditions. More severe catastrophic thoughts were strongly correlated with both generalised anxiety and anxiety ratings on the IBPQ, and thoughts were more catastrophic in 'unsafe' situations than in 'safe'. Regression analyses

identified 'catastrophic cognitions' as a strong predictor of both generalized and more specific anxiety, and this relationship was stronger for anxiety ratings on the IBPQ than for anxiety on the HADS. However, contrary to the hypothesis, satisfaction with social support was a particularly strong predictor of HADS anxiety, when 'catastrophic thoughts in safe situations' was included as an independent variable. However, cognitions explained more of the variance in generalized anxiety in unsafe situations than social support, raising the possibility that situational variables may be important moderators of severity of catastrophization, thereby mediating levels of anxiety.

4.2 METHODOLOGICAL CONSIDERATIONS

There were several limitations to this study. First, because of the high ratio of predictor variables to sample size, the results of the multiple regression analyses must be treated with caution. In addition to these problems, particular methodological concerns for the study include a relatively small sample size with possible biases in composition, and specific concerns about the appropriateness of the measures chosen. These will be discussed in more detail below.

4.2.1 The Sample

The sample size for this study was relatively small, making it difficult to draw firm conclusions from the results. Also, the self-selecting nature of the sample calls into question the representativeness of the findings, particularly for the prevalence of anxiety amongst this group. All the people contacted attended chest clinics, asthma clinics, or were involved with the pulmonary rehabilitation programme. It is likely that this presented a bias in the sample even before self-selection took place, as these people were more likely to have more severe symptoms, and, particularly for those attending rehabilitation programmes, may experience

more anxiety and cope less adequately with their illness than is really typical of this patient group. This bias may account for the unusually high level of anxiety reported in this study, which exceeds levels reported by some other authors (e.g. Prevalence rate of 16% - Karagji *et al.*, 1990). A large group of patients with COPD, particularly with milder forms of asthma, do not require continuing contact with these specialist services, and therefore would not have been considered by the physicians who selected suitable patients for the study. Of those who were contacted, 43% declined to take part, and of those who replied to the initial letter but declined, no reasons were given for this decision. It may be therefore, that the present sample did not include some of those who coped well with respiratory disease and did not experience significant anxiety. It is also possible that people who experienced significant anxiety may have declined to take part, if they felt that focusing on their respiratory problems may have increased their anxiety.

The gender spread amongst the sample was very evenly split, but age effects were harder to determine, as relatively few people took part who were below the age of 40. This was reflective of the later age of onset of some illnesses associated with COPD (e.g. bronchitis and/or emphysema). Clearly, a larger sample, which included a greater representation from patients whose experience of anxiety included those with low anxiety as well as those with extreme anxiety, would give a more representative view of the true nature of the experience of anxiety amongst this group of people.

4.2.2 The Measures

With regard to the measure of illness severity used in this study (SGRQ), it has been demonstrated to be highly correlated with actual physiological impairment, and was therefore

likely to be reliable self-report measure of severity. However, it would have been useful to include additional physiological respiratory function tests, such as Forced Expiratory Volume (FEV1) and Forced Vital Capacity (FVC) which are both spirometry measures of respiratory function, and have been used in many studies of respiratory disease (Porzelius *et al.*, 1992; van Peski-Oosterbaan *et al.*, 1996). Unfortunately, the author did not have access to, or the training to use these types of measure, and figures that could have been obtained from medical notes would have been out of date, as lung function may fluctuate. Other studies (Maes and Schlosser, 1988) have used a combination of amount and type of medication, number of hospital visits in the last year and duration of illness as a measure of severity. This was not used in this study as some studies have shown the resulting value is potentially less reliable as medication usage and visits to hospital are affected by other variables such as level of anxiety and adaptive coping mechanisms employed by the patient, regardless of actual impairment (Kinsman *et al.*, 1980; Kaptein *et al.*, 1988).

In previous studies (Porzelius *et al.*, 1992; Carr *et al.*, 1994) which have looked at the role of cognitions in anxiety and panic amongst patients with COPD, standardized measures have been used to assess for the presence of catastrophic thinking, such as the Agoraphobic Cognitions Questionnaire, and the Body Sensations Questionnaire, both developed by Chambless *et al.*, (1984). Use of these questionnaires may have been helpful in providing data which could be compared with that obtained in other studies, and may also have introduced another measure by which construct validity of the IBPQ could have been assessed. However, the decision not to use them was based on the fact that these measures were developed for therapy with other patient groups, and not specifically for people with respiratory disease. Clinical observations suggest that in addition to more general 'panic-related' cognitions, illness-specific cognitions

may be present in patients with COPD, and general questionnaires may not be sensitive to these, although they may have provided useful information on the extent of general catastrophization.

Cognitions and ratings of anxiety elicited by the IBPQ provided useful information on what participants anticipated they would think or do if they experienced the symptoms described in a range of situations presented. Unfortunately, practical limitations of a study such as this meant that there could be no *in vivo* assessment of thought, emotion or behaviour. This is a weakness of many questionnaires of this type, which rely on presentation of hypothetical scenarios to elicit thoughts, emotions and behaviours, (for example, The Body Sensations Interpretation Questionnaire (Clark, Salkovskis, Ost, Westling, Koehler, Jeavons, and Gelder, (submitted), on which the format and structure of the IBPQ was based).

The measure of generalized anxiety used in this study (HADS) was chosen because of it's appropriateness and acceptability to patients who have physical illness (Zigmond and Snaith, 1983). However, it is difficult to compare anxiety prevalence figures from this study to those in other studies with people with COPD, as a range of different measures have been used to assess anxiety levels in the various studies. For example, Yellowlees and colleagues (Yellowlees *et al.*, 1987), used a psychiatric interview to diagnose prevalence rates of 24% for panic disorder, with higher reported figures for anxiety, while much lower rates have been reported when other measures, such as the Stait-trait Inventory have been used (Light, Merrill, Despars, Gordon, & Mutalipassi, 1985). Also, in many studies, (e.g. van Peski-Oosterbaan *et al.*, 1996), prevalence figures for panic disorder are given, but there is less information on prevalence of other anxiety disorders. For valid comparisons to be made between studies, there needs to be greater use of equivalent questionnaires for measuring a particular variable. Related to this, it may have been

helpful to assess for panic disorder in the current study, as it is possible that some participants may experience more generalised panic-related cognitions in response to a variety of other symptoms, possibly unrelated to the respiratory disease (e.g. symptoms such as 'heart racing', palpitations, (Clark, 1986) in the absence of any respiratory-specific symptomatology).

4.3 INTERPRETATION OF RESEARCH FINDINGS

The prevalence of moderate to severe anxiety identified amongst this population of patients with COPD was comparable to the findings of Yellowlees *et al.* (1987). However, prevalence figures in both this and the current study were higher than those reported in other studies (e.g. Karagji *et al.*, 1988). The identification of such a high prevalence of anxiety is of particular concern as the experience of anxiety and panic has been found to worsen episodes of breathing difficulty, interfering with effective treatment (e.g. appropriate inhaler use), and potentially worsening the attack (Creer & Wigal, 1989). Kinsman *et al.* (1980) identified two types of anxiety associated with COPD; first, anxiety focused directly upon breathing difficulties, and second, anxiety characteristic of the person in many situations, regardless of the illness. Both forms of anxiety were associated with inappropriate excessive medication use in asthmatic in-patients, and greater levels of rehospitalization than for patients with lower levels of anxiety.

The finding that more severe catastrophic cognitions were significantly correlated with anxiety concurs with the findings of previous studies. Porzelius and colleagues (Porzelius *et al.*, 1992) found a strong association between anxiety and panic, with a high frequency of fear-provoking thoughts and concern with bodily symptoms (measured on the Agoraphobic Cognitions questionnaire (ACQ) and the Bodily Sensations questionnaire (BSQ)). In the current study,

cognitions were elicited from open-ended questions which presented a range of COPD-related symptoms in 'safe' and 'unsafe' situations. This latter measure may therefore have been more specific to the subjective experience of COPD symptoms than those used in the study by Porzelius *et al.*, which were developed for use with other clinical populations. Despite these methodological differences, the association between severity of catastrophic thoughts and anxiety remained strong in both studies.

Regression analyses indicated a clear predictive relationship between catastrophic cognitions and anxiety, which was stronger for specific anxiety ratings on the IBPQ than on the HADS measure of generalised anxiety. A recent study by Carr and colleagues (Carr *et al.*, 1995) also identified this predictive association, using a more general measure of catastrophic cognitions (ACQ). As in the current study, cognitions remained strongly predictive of anxiety, even when the frequency of dyspnea, severity of pulmonary impairment, and demographic variables were controlled for, supporting the appropriateness of applying the cognitive model, with its emphasis on the importance of catastrophic cognitions, in explaining anxiety.

In the current study, satisfaction with social support was also found to be strongly predictive of generalised (HADS) anxiety. This concurs with findings in studies by Sarason et al (1987) in which greater perceived social support was strongly associated with anxiety, as well as depression, somatization, and psychological disorder. This has important implications with regards to therapeutic interventions aimed at reducing anxiety levels, demonstrating that in addition to modification of catastrophic cognitions relating to COPD symptomatology, other factors, such as social support, must also be addressed.

The two measures of anxiety used in the current study assessed different aspects of anxiety, and this was reflected by the differences in strength of correlations and the extent to which each was predicted by catastrophic thoughts. The HADS reflects anxiety across a range of situations that occur over several days previous to assessment, but may not reflect peaks of anxiety that may be associated with exposure to certain symptoms and situations. The ratings of anxiety on the IBPQ were more specific according to symptom and the situation presented in each question. Ratings gave a prediction of how anxious participants felt they would be if they experienced the symptom presented in the situation presented. Although the association between catastrophic thoughts and anxiety was strong for both these measures of anxiety, the predictive relationship was stronger for IBPQ ratings of anxiety, which may be a reflection of how cognitions were specifically in response to the items presented on the questionnaire, and not more general in nature.

Both catastrophic thoughts and anxiety ratings in response to COPD symptoms in the 'unsafe' situations, were significantly more severe than in the safer situations. This may relate to the finding that there was significantly more avoidance of 'unsafe' situations than of the 'safe' situations. It may therefore be reasonable to hypothesise that many of the people who took part in this study rarely exposed themselves to some of the situations described, and hence would have been unlikely to have experienced symptoms in these situations. Avoidance of situations in which people have expectations of more catastrophic outcomes in the event of experiencing COPD-related symptomatology may be an important, but maladaptive, coping strategy to ensure high levels of anxiety are avoided. Cognitions related to 'safe' situations were significantly less catastrophic than in unsafe situations and were not significantly correlated with (or predictive of) HADS anxiety, even

though all seven symptoms were presented in both categories of safety. As in the Carr *et al.* (1995) study, severity and duration of illness were not significantly predictive of either measure of anxiety, and together, these findings support the application of a cognitive model to the genesis of anxiety and panic, and may also explain the reported higher levels of social isolation amongst this population (Kaplan *et al.*, 1988; Lehrer *et al.*, 1992).

The belief in more catastrophic consequences in 'unsafe' situations, and subsequent avoidance behaviour, may therefore reflect an unrealistic self-appraisal of ability to cope with symptoms in certain circumstances (e.g. being away from home without familiar people around). This has important consequences for therapy with people who have anxiety related to COPD. While HADS anxiety may reflect high levels of generalised anxiety, this may be masked in some people by avoidance behaviour which moderates exposure to situations in which catastrophic thoughts and consequent anxiety may be experienced. In these people, anxiety may be specifically related to the experience of symptoms in circumstances where they feel less confident, and may not be apparent without more specific assessment. An understanding of the thoughts associated with a patients' anticipated anxiety, assessed through a measure such as the IBPQ, may provide a valuable insight into the potential of an individual to become anxious in response to catastrophic thoughts about COPD symptoms.

Agle and Baum (1977) reported that patients with high levels of anxiety were less likely to benefit from rehabilitation programmes. Clinical experience with such programmes suggests that despite a reported increase in ability to cope in the home environment following participation in a rehabilitation programme, this improvement is often not reported to have generalised to situations where familiar people are not around or the patient is away from the home or a medical environment. The results of the current study may lead one to hypothesise that one reason for non-generalisability of benefits of rehabilitation in some people with COPD, may be due to anxiety-provoking catastrophic cognitions that have not been directly addressed, or even identified. This may result in impaired quality of life, which has been reported by numerous authors (Carr *et al.,* 1995; Kinsman *et al.,*1980; Lehrer *et al.*, 1992), and this would seem a valid focus for therapy.

4.4 CLINICAL IMPLICATIONS

Although treatment for COPD sufferers has improved substantially over the last three decades, therapeutic measures are effective only for symptom alleviation, and as yet, no cure has been found for the disease (Lee et al, 1991). Interventions therefore focus on minimizing the impact of the disability on the patients life. Even with improved preventative and ameliorative medication, patients' quality of life is still significantly impaired, with reports of more depression, anger, and fatigue than in a healthy population (Lee *et al.*, 1991).

The results of this study highlight areas for which there are important therapeutic implications. The finding that more severe catastrophic thoughts are predictive of anxiety, provides a useful focus for intervention, particularly in the context of knowledge about other important factors

which may moderate the severity of catastrophic thoughts, such as the perceived safety of the environment in which symptoms may occur. Results from completion of the IBPQ suggested that the high rates of avoidance of 'unsafe' situations in particular, may occur because of the anticipated anxiety associated with the possibility of experiencing symptoms related to COPD in situations where participants believed they would be at greater risk of becoming more ill, or even dying. The fact that severity of illness was not found to be an important factor in predicting anxiety in this study, as well as in previous studies (Carr *et al.*, 1995), provides further evidence that some people may avoid certain situations or activities because of unrealistic thoughts about the consequences of experiencing symptoms at these times.

An important goal of therapy then, would be to reduce the likelihood of a patient experiencing unnecessary self-imposed restrictions, unrelated to the actual severity of their illness, contributing to a lower quality of life, reduced opportunity for social support from community sources, and maintenance of unrealistic catastrophic cognitions about the consequences of symptoms. From studies with patients with other medical illnesses, catastrophizing has been shown to be an important factor in poor coping, and to be strongly related to greater disability (Petrie *et al.*, 1995; Smith *et al.*, 1986). Therapeutically, identification of patients with catastrophic cognitions and/or high levels of anxiety, is important in order that these patients may be targeted for therapy. An important focus for therapy would be on reduction of specific catastrophic cognitions associated with the illness, as opposed to using standard anxiety management techniques in which the focus may be on reducing more general anxiety. While high levels of generalised (HADS) anxiety may be a useful indication that more specific anxiety related to the respiratory disease may be present, a more specific evaluation of anxiety and particularly catastrophic thinking in relation to symptoms, is needed.

Since the physiological sensations are not likely to be eliminated, cognitive modification is an important treatment option for these patients. This treatment modality presents some unique challenges since treatment cannot consist of selective exposure to the bodily sensations which are chronic, or to hyperventilation, which may be hazardous. The severity of symptoms associated with COPD means that both catastrophic and depressogenic forms of appraisal have some basis in reality. However, cognitive-behavioural treatment can be helpful in obtaining a realistic sense of danger and help the patients to cope with their physical condition without the emotional suffering of panic or depression.

The focus of intervention may then be on cognitive restructuring of unrealistic or unhelpful catastrophic thoughts, which could then be tested out behaviourally through graded exposure to avoided situations (e.g. being away from the home or a medical environment) or circumstances (e.g. being alone). This type of intervention could be implemented through individual therapy, or in a group setting, such as through pulmonary rehabilitation groups, for which there may be the added benefit of providing additional social support through contact with other people with mutual experiences (Sarason *et al.*, 1988).

Pulmonary rehabilitation programmes constitute a comprehensive treatment approach based on symptom management and the promotion of energy and health. They usually comprise patient and family education, breathing training, systematic exercise, and patient support, provided by a multidisciplinary team of health professionals (Petty, 1993). There are obvious benefits to patients' quality of life from participation in programmes such as these, but personal clinical experience has also shown that these benefits often do not generalise to settings outside of the home environment or the medical unit in which programmes are usually run. Anxiety is rarely

treated using a structured cognitive approach, and the presence of catastrophic thinking that may underlie severe anxiety and maintain unrealistic beliefs about ability to cope with symptoms alone or away from home, has not been addressed in the literature on pulmonary rehabilitation.

'Satisfaction with (general) social support' was also a factor found to be significantly predictive of anxiety levels, with greater satisfaction predicting lower levels of anxiety. Studies (Sarason and Turk, 1983; in Sarason, Sarason and Pierce, 1988) have shown that perceived social support is more important than actual support with regards to adaptive coping with health problems. There is some evidence that family therapy, aimed at enabling the family to behave rationally and to optimally utilise medical services and interventions, may be associated with improved medication intake, and reduced impairment in daily functioning (Gustafsson, Kjellman, and Cederblad, 1986). Social support may be improved by helping patients with respiratory disease to realistically appraise their current levels of support, and providing information on social support networks, such as 'Breathe Easy' groups, which provide support for people with respiratory diseases through organised activities, providing information, and putting patients and their relatives in touch with others.

Thus far, there have been few evaluations of cognitive-behavioural interventions with people with COPD, although the use of cognitive therapy as part of psychoeducational self-management programmes for asthma has been found to be beneficial when compared with a no treatment control (Carr *et al.*, 1994; Emmelkamp and van Oppen, 1993). More research is needed before the full potential of this form of treatment can be evaluated, but the evidence from recent studies and the current study, of the presence of catastrophic thinking in response to

symptoms associated with COPD, and the relation of these to anxiety, lends support to this approach for therapy.

4.5 SUGGESTIONS FOR FUTURE RESEARCH

Completion of this study has heralded a number of areas in which further research may further current knowledge about the relationship of cognitions and anxiety in people with respiratory disease. Some of these are outlined below.

(i) Further statistical analysis of the psychometric properties of the IBPQ is needed before its reliability and validity can be fully reported on. It would be interesting to assess the predictive properties of the measure with regards to future anxiety, the potential success of a clients' engagement in individual therapy or a rehabilitation programme, and possible future disability and handicap.

(ii) Further testing of the application of the cognitive model of panic to people with COPD and concurrent high levels of anxiety is required. Firstly, a longitudinal design may provide more information than the current design which was mainly correlational. It would allow for teasing out of the complex inter-relationships between catastrophic thoughts, social support, anxiety, and behaviour, as well as allowing for evaluation of other variables that may be involved. Without studies of this nature, it is not possible to say whether changing catastrophic thoughts alone, will necessarily lead to a reduction in anxiety. Secondly, the model could be further tested through experimental manipulations. This may involve modifying, through focused psychological interventions, a particular aspect of one variable, e.g. extent of catastrophic cognitions, and evaluating the effect of this change on other variables.

(iii) It may be interesting to look at whether there is variation in the applicability of the cognitive model, according to the specific diagnostic groupings of patients (e.g. asthma, emphysema, bronchitis, etc) within the wider category of COPD.

(iv) There are likely to be many other variables that may also be affected by catastrophic thinking which, for reasons of limitations in time, and acceptability of the study to participants, were not included in this study. These may include self-medication patterns, self-management, self-efficacy beliefs, etc.

(v) A number of other factors have been shown to be related to high anxiety amongst people with respiratory disease. Lehrer *et al.* (1993; in Carr *et al.*, 1994) found that frequent experience of hyperventilation; reaction to asthma medications such as steroids; and negative emotion produced by having a chronic disease, to be implicated in provoking anxiety and other negative emotional states. It may be that none of these factors by itself is enough to produce anxiety, but in the presence of catastrophic cognitions, they could be hypothesised to increase vulnerability to anxiety and panic. Assessment of this hypothesis would be interesting, perhaps by employing a control group against which specific groups of patients could be compared.

(vi) In addition to those people who score very highly on anxiety scales, some people with high levels of avoidance may actually score relatively low on measures of generalized anxiety such as the HADS, as they are careful never to be exposed to situations they believe may have a dangerous outcome in the event of experiencing symptoms related to their respiratory disease. Further study may therefore be interesting, to see whether these people with low anxiety, have severe catastrophic thoughts specifically in response to COPD symptomatology.

(vii) Finally, it would be important to evaluate the involvement of other emotional problems, such as depression, for which there are also reportedly higher prevalence levels than are to be found in the general population (Lehrer *et al.*, 1993).

4.6 CONCLUSIONS

The major conclusions from this study are as follows:-

1. A significantly high prevalence of anxiety was found within a sample of 37 people with COPD. This was slightly higher than figures reported in other studies (e.g. Karajgi *et al.*, 1990), which may have reflected biases in the sample, and different assessment tools.

2. More severe catastrophic thoughts were related to higher levels of both generalised anxiety, and anxiety ratings on the IBPQ. This relationship was particularly strong when situations in which symptoms were presented were 'unsafe', indicating that the perceived safety of the environment may be an important moderator for catastrophic thinking.

3. Catastrophic thoughts were significantly predictive of anxiety, regardless of the severity and duration of illness. This relationship was more significant for anxiety ratings on the IBPQ than for HADS anxiety. Therapeutically, assessment of cognitions and anxiety specifically related to the respiratory disease is important, as more general measures of anxiety may not reflect the true extent of the emotional impact associated with COPD.

4. Greater avoidance of 'unsafe' situations was found than of 'safe', and may indicate unrealistic appraisals by patients of their true physiological state. Unrealistic catastrophic thoughts about consequences of becoming ill in situations away from the home environment or when alone may greatly impact on patients' quality of life, in an attempt to control for unnecessarily high levels of anxiety. For this reason, therapy should aim to elicit cognitions, and through cognitive restructuring, modify thoughts that may be unrealistic and catastrophic.

5. Less satisfaction with social support was significantly predictive of greater generalised anxiety, demonstrating the need for other factors in addition to cognitions to be addressed in therapy with people with COPD and severe anxiety.

6. The findings of this study need to be replicated with a larger sample of patients with COPD, and include evaluation of other variables that may affect severity of catastrophization and anxiety.

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APPENDICES

APPENDIX I - Letter to 6 people who took part in initial investigations

Dear

Study of people's mood and feelings about their breathing problems

I am a Trainee Clinical Psychologist based at the Hospital in , with , Chief Executive. I am currently carrying out a study looking at the mood and feelings people have in relation to their breathing problems, and how it may affect their life in general. We hope that this information will help in our understanding more about the experience of our patients.

Each person who wishes to take part would meet with myself, for up to 1 hour, either at the Hosptial, or if it is more convenient, I can visit people in their homes. This meeting would be relaxed and informal, and I will be asking questions about how people feel about their breathing problems, and how they affect everyday life. People will also be asked to fill in a short questionnaire.

I was given your name by , who was involved in running the Pulmonary Rehab. Group. If you would like to take part, please sign the form overleaf, and return it in the stamped addressed envelope, and I will contact you within the next week. All information will be anonymous and confidential, and you will not be identified in the report of the study. You are free to decide not to take part, and may leave the study at any time without it affecting your medical care. I have discussed the study with Dr. , Consultant General Physician, who is happy to support it. The study itself is subject to strict ethical regulations.

If you would like more information about any aspect of this study, then please do not hesitate to contact me at the above address.

Many thanks,

Yours sincerely

Karen Sutton
Trainee Clinical Psychologist

Chief Executive
(Supervisor)

APPENDIX II - Consent form

Corec No. 95-234

Consent Form

Study of People's Mood and Feelings about their Breathing Disorder

Please complete this sheet.

Have you read the information letter? Yes/No

Have you had an opportunity to ask questions and discuss the study? Yes/No

Have you received enough information about the study? Yes/No

If your answer is 'No' to any of these questions, and you feel you would like some more information before agreeing to take part in the study, then please tick below and I will be happy to contact you. Tick here.....

Do you understand that you are free to leave the study:

- **at any time,**
- **without having to give a reason for leaving**
- **and without affecting your medical care? Yes/No**

Do you wish to take part in the study? Yes/No

Signed:_____ **Date:**_____

Name (in block letters):_____

(If you wish to take part, and you do not mind being contacted by phone, please write your number below so I can contact you more easily. Thank you).

Phone number:_____

APPENDIX III - Letter to potential participants for main study

I can be contacted on:

Date:

Dear

Study of people's mood and feelings about their breathing problems

I am a Trainee Clinical Psychologist based at the Hospital in with , Chief Executive. I am currently carrying out a study looking at the mood and feelings people have in relation to their breathing problems, and how it may affect their life In general. We hope that this information will help in our understanding more about the experience of our patients.

The study would involve each person who agrees to take part, completing 5 short questionnaires. These usually take about 45 minutes in total, and can be done either at the chest clinic, or at home if this is more convenient. I will be present to answer any questions or concerns people may have while they are answering questionnaires.

The names of patients who attend the Chest Clinic here in , have been forwarded to me as people who may be suitable to take part in this study. If you would like to take part, please sign the form overleaf, return it in the envelope provided, and I will contact you within the next week. If you decide not to take part, please return the form anyway and I will not contact you again. All information will be anonymous and confidential, and you will not be identified in the report of the study. You are free to decide not to take part, and may leave the study at any time without it affecting your medical care. I have discussed the study with Dr. , Consultant General Physician, who is happy to support it. The study itself is subject to strict ethical regulations.

If you would like more information about any aspect of this study, then please do not hesitate to contact me at the above telephone number, (if I am not there, please leave a message and your telephone number, and I will phone you back as soon as possible).

Many thanks,

Yours sincerely

Karen Sutton
Trainee Clinical Psychologist (Supervisor)

APPENDIX IV - Reminder letter to people who did not reply to original letter

Date:

Dear ,

I wrote to you recently to ask if you would like to take part in a study which is looking at the relationship between anxiety and thoughts in people with a range of breathing disorders. I am writing to everyone who so far has not replied to my original letter. As I have not heard from you as yet, I was wondering if you would like to take part, or whether you would prefer not to. I would be grateful if you could fill in the consent form stating whether or not you wish to take part, and return it in the stamped addressed envelope enclosed in the original letter. If I do not hear from you within the next fortnight, I will assume that you do not wish to take part in the study.

If you would like further details, I can be contacted on . If I am not there, you can leave a message and I will call you back as soon as possible.

I look forward to hearing from you.

Yours sincerely

Karen Sutton

Clinical Psychologist in Training

APPENDIX V

Summary of Interview for Initial Investigation (for development of IBPQ)

1. General information:

   Age, sex, diagnosis, duration of illness, frequency of severe breathing difficulties, and medication.

2. Frequency of experiencing the following symptoms (taken from the 'Asthma Symptom Checklist' and the 'Bronchitis and Emphysema Symptom Checklist'):

   Chest pain, numbness, tightness in chest, chest congestion, shortness of breath, hard to breathe, wheezing, chest 'filling up', tiredness, exhaustion, no energy, weakness, a lot of mucous, coughing, feeling of chest being over expanded, needing fresh air.

3. Any thoughts that the person may have when they experience any of the symptoms above.

4. Direct question:

   Do you ever think 'I'm going to die', 'I'll cope', etc?

5. How anxious would you feel if you experienced each of the symptoms above(on a scale of 1-8).

6. Do you avoid any of the following situations or activities in order to reduce the likelihood of experiencing an episode of breathing difficulty?

   Being alone, drinking alcohol, smoking, going out with friends, walking for 5 minutes, walking for 10-20 minutes, going upstairs, travelling alone by bus etc, being in a crowd, going out alone, not having medication close at hand, exercise, drinking coffee.

   Are there any other situations you avoid?

APPENDIX VI

Interpretation of Breathing Problems Questionnaire

This questionnaire has been developed specifically for people with breathing problems including asthma, bronchitis and emphesema. It is designed to assess peoples' thoughts in response to various symptoms they experience as a result of their breathing problem.

Here are some descriptions of some of the symptoms you may experience in relation to your breathing problem. A variety of situations are described in which each symptom may be experienced. Read each one, and then answer the questions below it very briefly. Write down the first thing that comes into your mind without thinking too long about it. You may not have experienced all of the symptoms or the situations described in the questions. If this is the case, please answer the question anyway, by imagining how you would respond to the symptom in the situation described.

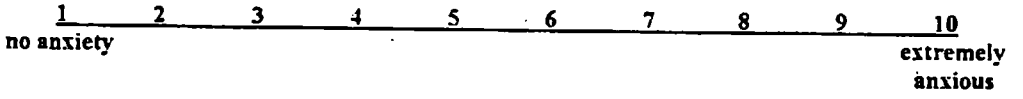
Each question also asks you to rate how anxious you think you would be in each situation, and what you believe could happen to you. Ratings are made on a scale of 1-10, and instructions on how to respond are given for each question.

1. You are in a smokey pub and your chest begins to feel tight.

What might you do in this situation?

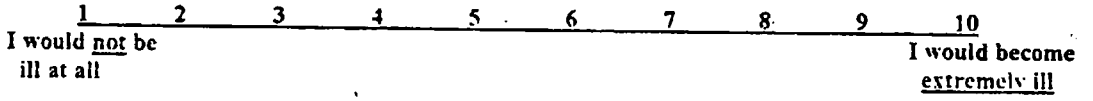
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

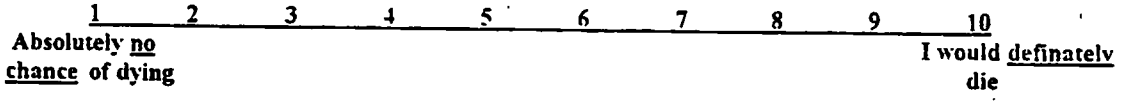


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



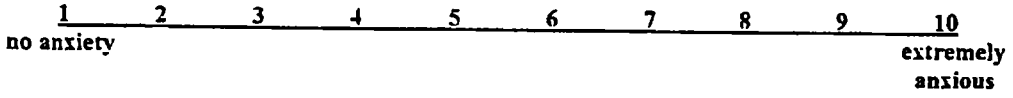
Would you avoid this situation?.....yes / no

2. You are at a friends' house, and your chest begins to feel tight.

What might you do in this situation?

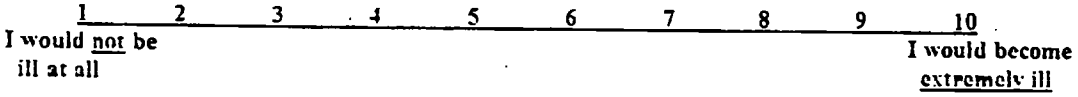
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

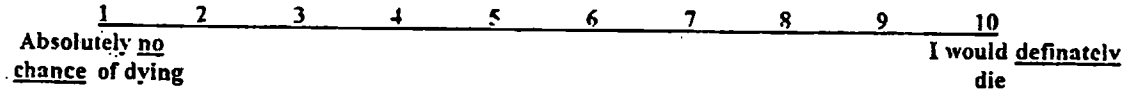


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



Would you avoud this situation?.....yes / no

3. You are going up the stairs at a shopping centre and you notice it is becoming harder to breathe.

What might you do in this situation?

What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

1 2 3 4 5 6 7 8 9 10

no anxiety — extremely anxious

Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?

1 2 3 4 5 6 7 8 9 10

I would not be ill at all — I would become extremely ill

2. How much do you believe you would die **in this situation**?

1 2 3 4 5 6 7 8 9 10

Absolutely no chance of dying — I would definately die

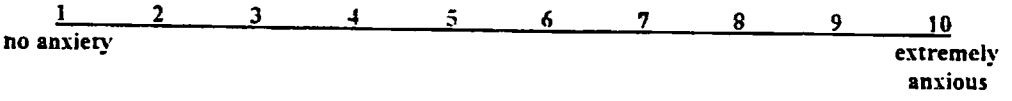
Would you avoid this situation?.....yes / no

4. You are in a crowd in town, and you begin to feel tired and exhausted.

What might you do in this situation?

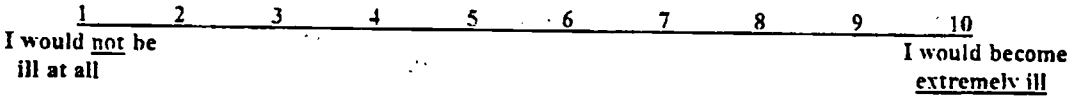
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

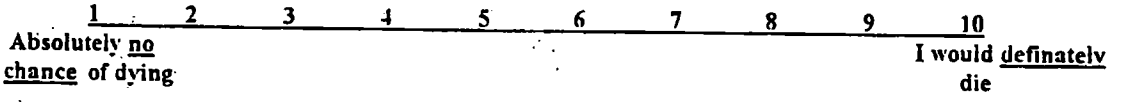


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



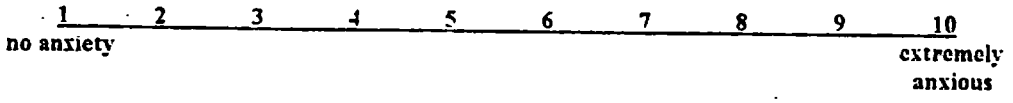
Would you avoid this situation?.....yes / no

5. You are going up the stairs at home, and you notice it is becoming harder to breathe.

What might you do in this situation?

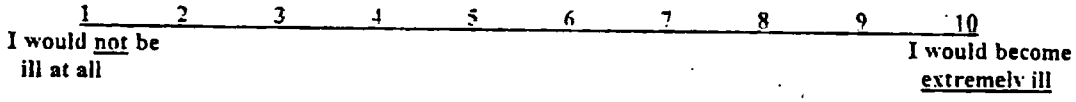
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

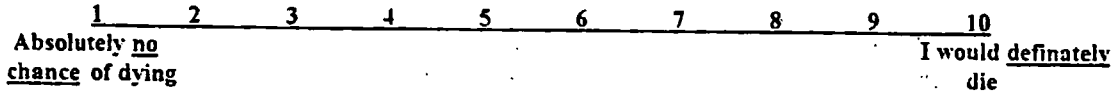


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



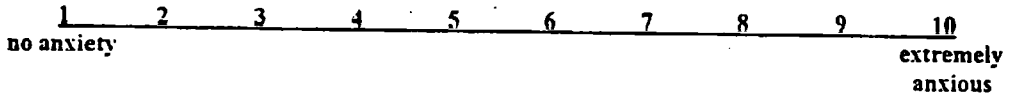
Would you avoid this situation?.....yes / no

6. You are sitting at home with a friend, and you notice you are wheezing.

What might you do in this situation?

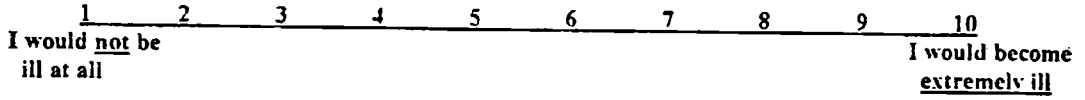
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

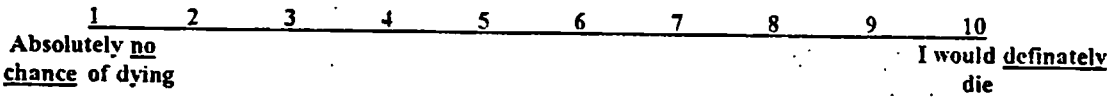


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



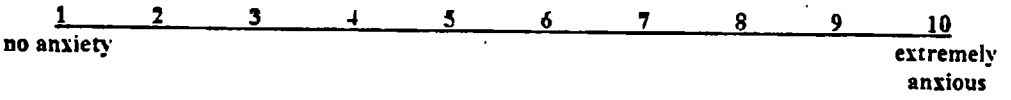
Would you avoid this situation?.....yes / no

7. You are driving down the motorway, and you notice your chest is becoming congested.

What might you do in this situation?

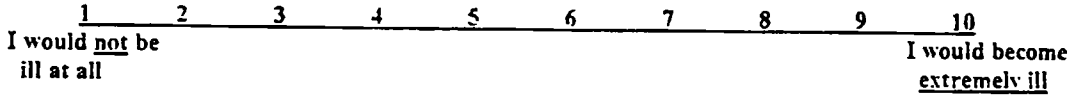
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

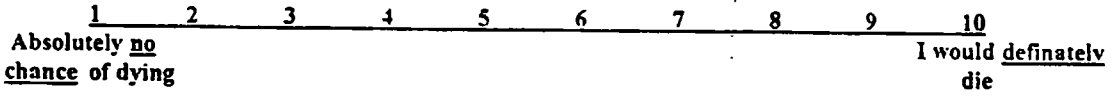


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



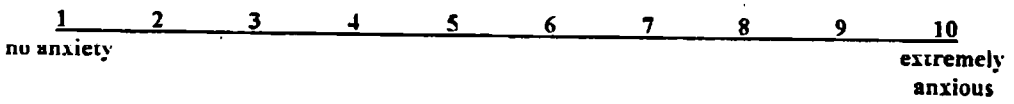
Would you avoid this situation?.....yes / no

8. You are at your G.P. surgery, and you begin to cough heavily.

What might you do in this situation?

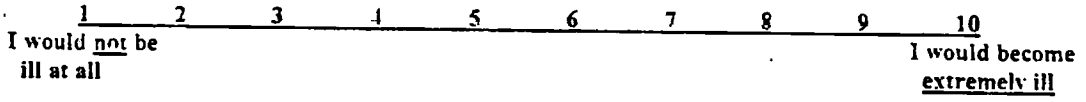
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

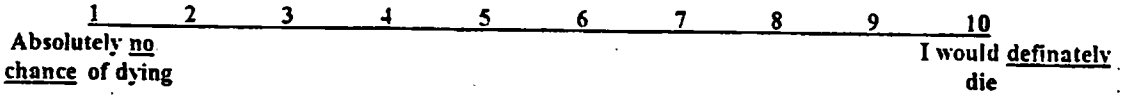


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



Would you avoid this situation?.....yes / no

9. You are visiting a physiotherapist at the hospital, and you feel your chest is becoming congested.

What might you do in this situation?

What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

1 2 3 4 5 6 7 8 9 10

no anxiety — **extremely anxious**

Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?

1 2 3 4 5 6 7 8 9 10

I would not be ill at all — **I would become extremely ill**

2. How much do you believe you would die **in this situation**?

1 2 3 4 5 6 7 8 9 10

Absolutely no chance of dying — **I would definately die**

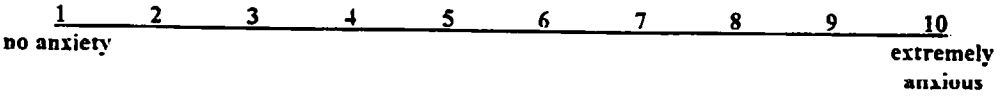
Would you avoid this situation?.....yes / no

10. You are on a crowded bus and you notice you are wheezing.

What might you do in this situation?

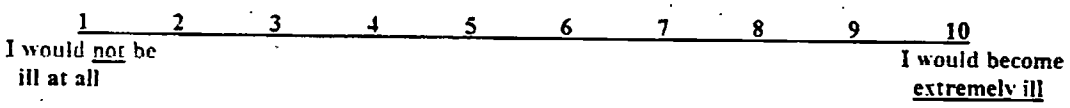
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

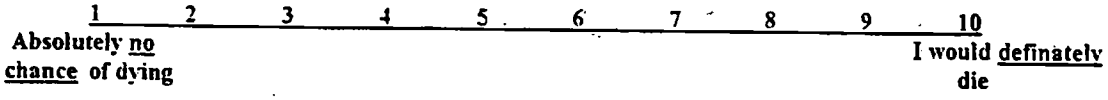


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



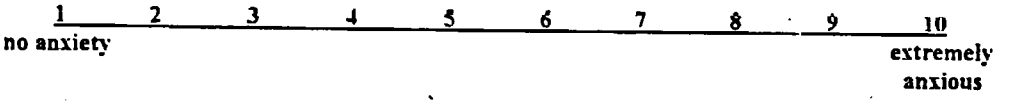
Would you avoid this situation?.....yes / no

11. You are out working in your garden with a friend, and you notice you are short of breath.

What might you do in this situation?

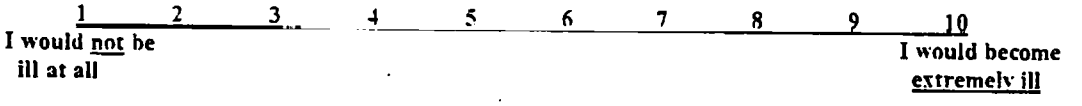
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

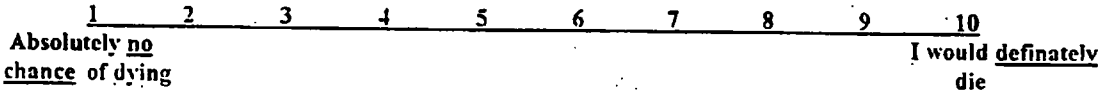


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



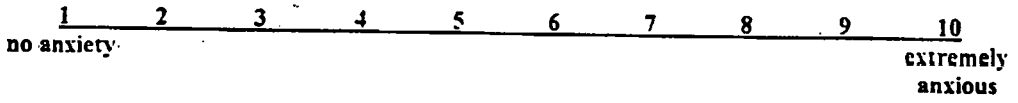
Would you avoid this situation?.....yes / no

12. You are in the supermarket, and you begin to cough heavily.

What might you do in this situation?

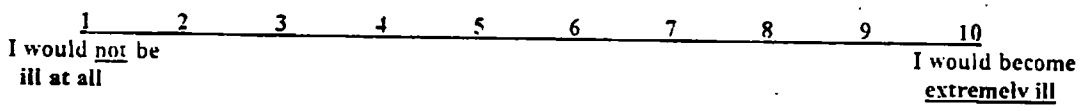
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

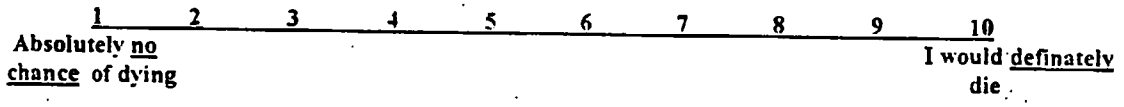


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill **in this situation**?



2. How much do you believe you would die **in this situation**?



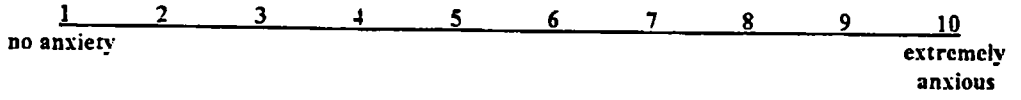
Would you avoid this situation?.....yes / no

13. You are at the hospital for a check-up, and you begin to feel tired and exhausted.

What might you do in this situation?

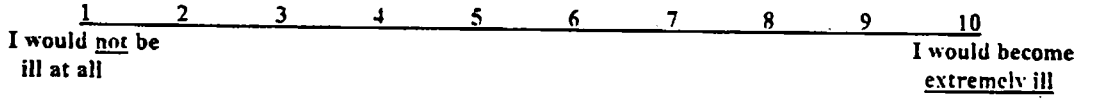
What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

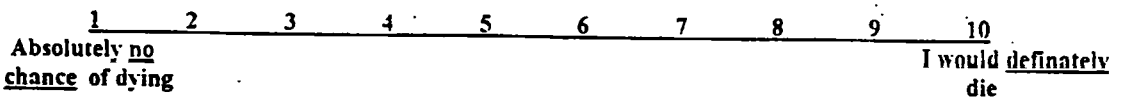


Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill in this situation?



2. How much do you believe you would die **in this situation**?



Would you avoid this situation?.....yes / no

14. You are out on a long walk on your own, and you notice you are short of breath.

What might you do in this situation?

What thoughts go through your mind?
What is the worst thing that you think may happen to you?

Please rate how **anxious** you would be **in this situation**, by marking the scale below:

1 2 3 4 5 6 7 8 9 10

no anxiety — extremely anxious

Please answer the 2 questions below by marking each scale:

1. How much do you believe you would become ill in this situation?

1 2 3 4 5 6 7 8 9 10

I would not be ill at all — I would become extremely ill

2. How much do you believe you would die **in this situation**?

1 2 3 4 5 6 7 8 9 10

Absolutely no chance of dying — I would definately die

Would you avoid this situation?.....yes / no

Thank you for completing this questionnaire - please check through it to ensure you have answered all 14 questions as pages often stick together!

Hospital Anxiety and Depression Scale (HADS)

NFER NELSON

Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

A	D		A	D
		I feel tense or 'wound up'		
3		Most of the time		
2		A lot of the time		
1		From time to time, occasionally		
0		Not at all		
		I still enjoy the things I used to enjoy		
	0	Definitely as much		
	1	Not quite so much		
	2	Only a little		
	3	Hardly at all		
		I get a sort of frightened feeling as if something awful is about to happen		
3		Very definitely and quite badly		
2		Yes, but not too badly		
1		A little, but it doesn't worry me		
0		Not at all		
		I can laugh and see the funny side of things		
	0	As much as I always could		
	1	Not quite so much now		
	2	Definitely not so much now		
	3	Not at all		
		Worrying thoughts go through my mind		
3		A great deal of the time		
2		A lot of the time		
1		Not too often		
0		Very little		
		I feel cheerful		
	3	Never		
	2	Not often		
	1	Sometimes		
	0	Most of the time		
		I can sit at ease and feel relaxed		
0		Definitely		
1		Usually		
2		Not often		
3		Not at all		
				I feel as if I am slowed down
				Nearly all the time
				Very often
				Sometimes
				Not at all
				I get a sort of frightened feeling like 'butterflies' in the stomach
			0	Not at all
			1	Occasionally
			2	Quite often
			3	Very often
				I have lost interest in my appearance
			3	Definitely
			2	I don't take as much care as I should
			1	I may not take quite as much care
			0	I take just as much care as ever
				I feel restless as if I have to be on the move
			3	Very much indeed
			2	Quite a lot
			1	Not very much
			0	Not at all
				I look forward with enjoyment to things
			0	As much as I ever did
			1	Rather less than I used to
			2	Definitely less than I used to
			3	Hardly at all
				I get sudden feelings of panic
			3	Very often indeed
			2	Quite often
			1	Not very often
			0	Not at all
				I can enjoy a good book or radio or television programme
			0	Often
			1	Sometimes
			2	Not often
			3	Very seldom

Now check that you have answered all the questions

A	D	
		TOTAL

APPENDIX VIII

Scoring Bands for the HADS

Range of scores	Interpretation
0-7	**normal**
8-10	**mild**
11-14	**moderate**
15-21	**severe**

Snaith and Zigmond (1994)

It should be noted that althought these definitions were used in this study, the HADS may now be interpreted in clinical situations in the following way:

0- 7 no anxiety

8-10 possible anxiety

11+ probable anxiety

APPENDIX IX

St. Georges Hospital Respiratory Questionnaire

This short questionnaire is designed to help us learn more about how your breathing is troubling you. Please read the instructions carefully, and ask if you do not understand anything. Do not spend too long thinking about your answers.

Thank you.

QUESTIONS ABOUT HOW MUCH CHEST TROUBLE YOU HAVE HAD OVER THE LAST YEAR. PLEASE TICK IN ONE BOX FOR EACH QUESTION.

	most days a week	several days a week	a few days a month	only with chest infections	not at all
1) Over the last year, I have coughed :	O	O	O	O	O
2) Over the last year, I have brought up phlegm (sputum) :	O	O	O	O	O
3) Over the last year, I have had shortness of breath :	O	O	O	O	O
4) Over the last year, I have had attacks of wheezing :	O	O	O	O	O

5) During the last year, how many severe or very unpleasant attacks of chest trouble have you had :

- more than 3 attacks..... O
- 3 attacks..... O
- 2 attacks..... O
- 1 attack..... O
- no attacks..... O

6) How long did the worst attack of chest trouble last:
(Go to Question 7 if you had no severe attacks)

- a week or more..... O
- 3 or more days..... O
- 1 or 2 days..... O
- less than a day..... O

7) Over the last year, in an average week, how many good days (with little chest trouble) have you had:

- none..... O
- 1 or 2..... O
- 3 or 4..... O
- nearly every day..... O
- every day..... O

8) If you have a wheeze, is it worse in the morning:

- no..... O
- yes..... O

SHORT FORM SOCIAL SUPPORT QUESTIONNAIRE (SSQ6)

NFER NELSON

Name:.....

Date:..... Age:..... Sex: M F

Instructions

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give each person's initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath each question. Do not list more than nine people per question.

For the second part, using the scale below, circle how satisfied you are with the overall support you have.

6	5	4	3	2	1
Very satisfied	*Fairly satisfied*	*A little satisfied*	*A little dissatisfied*	*Fairly dissatisfied*	*Very dissatisfied*

If you have no support for a question, tick the words 'No one', but still rate your level of satisfaction. The example below has been completed to help you. All your responses will be kept confidential.

Example

Who do you know whom you can trust with information that could get you in trouble?

(a) No one
1) TEN (Brother)
2) LM (Friend)
3) ASS (Friend)
4) PEN (Father)
5) LM (Employer)
6)
7)
8)
9)

(b) How satisfied? 6 5 (4) 3 2 1

(1) Whom can you really count on to distract you from your worries when you feel under stress?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

(2) Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

(3) Who accepts you totally, including both your worst and best points?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

(4) Whom can you really count on to care about you, regardless of what is happening to you?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

(5) Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

(6) Whom can you count on to console you when you are very upset?

(a) No one 3) 6) 9)
1) 4) 7)
2) 5) 8)

(b) How satisfied? 6 5 4 3 2 1

Background Information for Research

Name/Code..... Date.....

Age..... D.O.B..... Sex M / F

Referred Through:.....

Diagnosis.....

Duration of Illness.....

Medication.....

.....

Total number of visits to hospital/casualty for illness.....

Visits in last year..... Average duration of visits.....

Questionnaires completed:

Breathing Problems Qu. .....

IPQ .....

HADS .....

St. Georges Qu. .....

'Safe'/'Unsafe' Ratings .....

APPENDIX XII

Original Ethics Proposal

The original proposal to the ethics committee was made before the IBPQ had been developed. Consequently, subsequent ammendments were made to this proposal which are outlined in Appendices XIII to XV. Part of the title on the original proposal was changed from 'misinterpretations of bodily symptoms' to 'catastrophic thoughts' as this was felt to be rather less misleading with regards to the aim of the study.

CENTRAL OXFORD RESEARCH ETHICS COMMITTEE FORM CONFIDENTIAL

Valid Until July 1995

Please complete using a typewriter or printer that keeps this layout.

COREC number

1. Title of Study

The relationship between anxiety and misinterpretations of bodily symptoms in pa tients with chronic pulmonary disease.

2. Principal Investigator(s)

	1.	2.	3.	4.
Names	Karen Sutton	Louise Wallace (Supervisor)		
Qualifications	BSc Psychol. (Hons)	BSc, MSc, PhD, MBa, FBPS (Psychol).		
Position	Trainee Clinical Psychologist	Chief Executive		
Employing Authority Contract (none,hon,full,P/T)	Oxford Reg. Health Auth. (full)	Hospital NHS Trust (full)		

3. Address for correspondence (the Principal investigator is responsible for keeping the other investigators informed)

Karen Sutton, Oxford Regional (in Service) Training Course in Clinical Psychology, Isis Education Centre, Warneford Hospital, Headington, CXFORD.

4. Work & Home Telephone numbers for enquiries

Work: 01865 226431. Home: 01491

5. Where will the research be done? Hospital.

Is the study to be multi-centre? Yes/No

6. Has this application gone to other Ethics Committees? Yes/No

7. When would the study start and finish? October 1995 - July 1996

8. What arrangements have been made for indemnity?

8a. If the study has drug-company funding, has the company signed the standard indemnity letter from your employing authority (see note below)? Yes/No

8b. If you are employed in an NHS Trust, has it agreed to indemnify you for this research? Yes/No
→ Honorary Contract to be issued by Gen. Hospital.

8c. If you are employed by the University, has it agreed to indemnify you for this research? Yes/No

8d. If you are self-employed, or the answers to 8a, 8b and 8c are no, what is your medical indemnity? _____

The letter of agreement between your employers and a drug company should follow the ABPI guidelines, and it must be signed by both your employer and by the drug company. Standard letters may be obtained from Trust Chief Executives/Medical Directors. A copy of the indemnity letter should be sent to COREC.

N.B. Chronic Obstructive Pulmonary Disease = COPD

9. Scientific background of the study

Research suggests that patients suffering from COPD experience higher than average levels of anxiety and depression, (Lehrer et al,1992). Causality of anxiety is likely to be part of a complex mechanism mediated in some patients by misinterpreting certain normal bodily functions as indicators of an imminent breathing difficulty related to COPD, (Paul Bennett, perso communication).

Physical exercise rehabilitation programmes have a significant impact on the quality of life of these patients (Petty,T. 1993). There is also evidence that additional psychological approaches can significantly reduc illness-related anxieties (Lehrer et al, 1992). Identification of the factors involved in the mediation of anxiety in pulmonary patients is therefore highly important in setting up an effective management programm to complement existing rehabilitation services.

10. Has a similar study been done previously? Yes/(No) If yes, why repeat it?

11. Purpose of project, in terms that a non-medic could understand.

The aim of this study is to see if there is a relationship between high levels of anxiety in some patients with COPD, and frequent misinterpretin of normal bodily functions (eg. shortness of breath after exercise) as a sign of a serious breathing difficulty. If such a relationship exist patients can be taught to discriminate between genuine warning signs, and normal breathing, and hence reduce anxiety levels.

12. Design of study (a *summary* of the protocol, including the reasons for the number of subjects in Q 13):

1. Development of misinterpretations questionnaire: 5 participants who consent will be informally interviewed in order to ascertain common thoughts and worries relating to their illness. The information will be incorporated in a questionnaire based on the 'Interpretations Questionnaire' enclosed (see page 10). The HADS will also be given for completi
2. Main Study: With the agreement of the consultant Physician, a minimum o 50 adult outpatients attending respiratory clinics will be given informat about the study. The principal investigator will meet with each patient who consents to take part to discuss any queries they may have, on an individual basis. The questionnaires will then be presented, and partic pants asked to complete them. Again, the investigator will be present if there are any queries. This will be carried out either at routine outpatient appointments at the clinic, or in the participants home if this is more convenient. All questionnaires will be coded for anonymity and kept in a locked filing cabinet at the Horton Hospital.
3. Test-Retest reliability of the misinterpretations questionnaire: The questionnaire will be sent to each participant to be filled in again, 4 weeks after they originally completed the initial battery of tests. Questionnaires can be returned by pre-paid postage.

13. SUBJECTS

	Healthy people	Patients	Control Patients
Number to be studied		50.	
Inclusion criteria		People with COPD (including asthma, emphesema, etc) All=outpatients	
Exclusion criteria		People with additional serious physical or mental health problems.	
Age range Males: Females:		18 -80 years equal male:female if possible.	
Method of recruitment		Patients attending respiratory clinics - opt-in procedure after info. sheet presented.	

14. What procedures will the subjects have? Include exercise tests, ECGs, catheterisation, X-rays lasers, ultrasound, microwaves, shortwaves, MRI and radio-isotopes, and state the estimated risk from these procedures.

Participants will be asked to complete 3 questionnaires. These will be completed in a quiet room to maintain confidentiality, or in the person's home if they prefer. Completion of the questionnaires should take up to 30 minutes, and the principal investigator will be present to answer questions participants may have. Additionally, the misinterpretations questionnaire will be sent to participants 4 weeks after the original completion, to assess test-retest reliability over time.

There is NO estimated risk from this procedure.

15. What samples will be taken extra to normal care? Do any carry risks?

N/A

16. What events or measurements will be the main endpoints in your study?

Scores on each questionnaire for each participant will be entered into a regression analysis.

Information and Consent

Please read the notes carefully when answering this section.

21. Who will give the verbal explanation of the study to the subject?

Principal Investigator, Karen Sutton.

Please append the letter inviting subjects to take part and explaining the study, as it will appear - i.e. using your letterhead, etc. If there is no written invitation and explanation, please justify.

22. How long will the subject have between the explanation and being asked to take part? If less than 24 hours, please justify.

Minimum 1 week.

23. Will you use the Royal College of Physicians' consent form? (Yes) No

If not, please explain

24. Do you have the agreement of other doctors and nurses involved in the care of the patients? (Yes) No

Please attach the letter to the subjects' general practitioner. (Please see page 10)

25. Please say what funds will be used and who will be paid for the study, and state the payment per patient if this is the method of funding

Questionnaires will be funded by a budget held by the Oxford Reg. Training Course. There will be no other overheads.

The principal investigator must sign that he or she

* affirms that the information in this application is true.
* understands the obligations to, and the rights of, the subjects, particularly in giving of information and obtaining of consent.
* and will ensure that the patient's hospital medical records are marked to say that the patient is in a study, giving the title and COREC number for reference

26. Signature: Karen Sutton
Date: 20/9/95

NAME in CAPITALS KAREN SUTTON

27. CONSULTANT/HEAD OF DEPARTMENT: should sign that he or she has discussed the research application with the investigator, and supports the application.

* **Signature:**
Date: Please see attached memorandum from Louise Wallace. *

NAME in CAPITALS:

APPENDIX XIII

Initial reply from ethics committee, following discussion with committee member to explain details of study

CENTRAL OXFORD RESEARCH ETHICS COMMITTEE
Oxfordshire Health
Directorate of Public Health & Health Policy
Manor House, Headley Way
Headington, OXFORD OX3 9DZ
Tel: Oxford (01865) 222547
Fax: Oxford (01865) 222777
Please reply to Miss Ellen Hearth

Our Ref: RMW/EH/PS/95-234
Your Ref:

17th October 1995

Ms Karen Sutton
Trainee Clinical Psychologist
Oxford Regional (in Service)
Training Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

Dear Ms Sutton,

RE: COREC: 95-234 - The relationship between anxiety and misinterpretations of bodily symptoms in patients with chronic pulmonary disease

has told me about his discussion with you on this proposed research. It appears that COREC did not understand the background to the questions that you proposed to put to patients with C.O.P.D. I gather that you are modifying the questions. If you would send me the revised questionnaire, with some more information about the validity of the questions, I shall see if I can give you Chairman's approval as soon as possible.

Yours sincerely,

Dick Mayon-White.

Dr R Mayon-White
Vice Chairman
Central Oxford Resesrch Ethics Committee

APPENDIX XIV

Letter granting ethical approval, following submission of IBPQ

OXFORDSHIRE HEALTH

OXFORDSHIRE HEALTH AUTHORITY
OXFORDSHIRE FAMILY HEALTH SERVICES AUTHORITY

CENTRAL OXFORD RESEARCH ETHICS COMMITTEE
Stable Block, Headley Way, Headington, Oxford, OX3 9DX
Tel: 01865 222547
Fax: 01865 222777

Our Ref: RC/KLB/PS/95.234

22nd January 1996

Ms Karen Sutton
Trainee Clinical Psychologist
Oxford Regional (in Service)
Training Course in Clinical Psychology
Isis Education Centre
Warneford Hospital

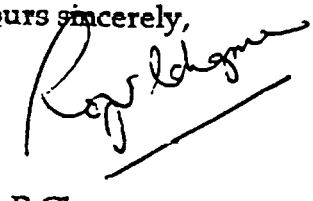
Dear Ms Sutton,

RE: COREC: 95.234 - The relationship between anxiety and misinterpretations of bodily symptoms in patients with chronic pulmonary disease

Thank you for letting me have the further details on this project. I am happy to confirm ethical approval, and wish you every success with the study. I would be very grateful if you could send me a copy of any publication which may arise from this study.

You should inform COREC of any adverse affects or events. In addition, if the investigators do not follow the protocol, or have protocol changes, but fail to inform COREC, then the Ethics Committee approval will be withdrawn and will no longer be binding.

Yours sincerely,



Dr R Chapman
Consultant Physician
Chairman
Central Oxford Research Ethics Committee

APPENDIX XV -
Further changes to original ethics applications

Following the letter (22nd January, 1996) giving ethics committee approval for the study to go ahead using the IBPQ, three further letters were sent to the committee, each asking for (and receiving) approval for specific changes. Due to shortage of space, I have summarised these applications - for copies of actual letters, please contact the author.

1. 11/2/96:

(i) Changes to format of original IBPQ
(ii) Application for open-ended responses on IBPQ to be judged by independent raters.
(iii) Application for use of the St. Georges Respiratory Questionnaire, with information on reliability and validity.

Approval received: 21/2/96.

2. 21/2/96:

(i) Application to send 'reminder letter' to people who had not replied to original.

Approval received: 28/2/96.

3. 4/4/96:

(i) Application to use Short Form Social Support Questionnaire-6.

Approval received: 12/4/96.

APPENDIX XVI - Cover letter to participants who agreed to take part in the retest-condition

Dear

Following my visit to your house a few weeks ago to complete some questionnaires on different aspects of your breathing problem, I am sending you one of them to complete again, as you kindly agreed to do this when we met. You will probably remember completing the (long) 'Interpretation of Breathing Problems' questionnaire when I saw you - instructions are on the front sheet if you need them. The second questionnaire is a measure of your view of the social support you receive from family, friends, health professionals, etc. I have included it in the study as it has been shown to provide useful information about where people obtain most of their support, and can be related to how they cope with the breathing problem. I apologise for its late inclusion in the study and I hope that you do not mind completing it as well. As before, the questionnaires you complete will be totally anonymous and you will not be identifiable in any way in the write-up. Instructions for completion are on the front sheet, but if you have any problems with either this questionnaire, or the other one, please do not hesitate to call me on , and if I am not there, I will phone you back as soon as possible. I have enclosed a stamped addressed envelope for you to return the completed questionnaires in.

Once again, I would like to thank you for sparing me the time to complete these questionnaires and helping me with this study. It seems to be going quite well, and I have particularly enjoyed meeting so many people who are willing to share their experiences with me.

I wish you well in the future.

Yours sincerely,

Karen Sutton

Clinical Psychologist in Training

APPENDIX XVII

Rating criteria of open-ended responses

(severity of catastrophic thoughts)

1 = Non-catastrophic:

Responses that imply that the participant is not at all worried about the symptom described, e.g. 'I'll be fine', 'I'll cope OK', 'Nothing will happen', etc.

Any response that implies **no** adverse consequences **with regard to symptoms becoming more severe.**

Reactions reflecting irritation or embarrassment at experiencing problems that inconvenience the participant, but not with regards to exacerbation of symptoms, e.g. 'I'll find a toilet where I can cough without anyone seeing me', 'I'll be late, but I'll be OK', etc.

2 = Moderately catastrophic:

Answers implying a moderate consequence with regards to exacerbation of symptoms, e.g. symptoms will become worse, but implication that this is not distressing, or that the participant is able to cope, e.g. 'My breathing will become worse', 'If I don't sit down, I'll become more breathless', etc.

3 = Severely catastrophic:

Answers implying a severe consequence of specific breathing related problems, in which the participant clearly expresses a thought reflecting a consequence that may put them in danger, e.g. thoughts of collapse, suffocation, and death.

APPENDIX XVIII

Table 19: Examples of open-ended responses from IBPQ

Category of Response	*Examples of responses*
Non-catastrophic	'I'm OK because the Dr. is here, so even if I get worse I'll be OK' 'I'll cope because my husband is always here (*at home*) with me' 'Embarrassed (*at wheezing in company*), but I'll take my ventolin and be fine' 'I'll be alright after a rest' 'No problems!' 'I'm in the right place (*hospital*) if it does get worse' 'I'll be OK - I've got my medication with me' 'I'll ignore it and it will go away' 'I'll be OK after a puff (*on inhaler*)' 'I'm in safe hands (*with physiotherapist*)' 'I've eaten too much - it's nothing to do with my breathing' 'Really annoyed - this always happens (*short of breath*) and I'll be late' 'Hope no-one notices - embarrassed' 'Very angry - I can't even do my shopping without coughing'
Moderately catastrophic	'I'm going to have a breathing problem' 'I won't be able to catch my breath' 'I must slow down and take my ventolin or it (*breathing*) will get worse' 'I'll get dizzy and breathless' 'Concerned - I'll become uncomfortable' 'I have to get out (*of supermarket*) because I'm embarrassed and I wouldn't know if it will get worse' 'My breathing will become worse but I won't die' 'Try to calm down - concerned I'll get worse' 'Embarrassed and angry - worried I'll get ill' 'Worried if I'm alone incase I feel worse' 'Worried because I'm not at home or with friends'
Severely catastrophic	'I must get out (*of smokey pub*) - very anxious - I'll collapse' 'I'll stop breathing and get brain damage' 'I haven't got much time before I collapse' 'It (*wheezing*) will get worse - I won't be able to breathe and I wouldn't have any oxygen with me' 'Can't breathe - might die' 'I'll lose control and no-one can help me' 'I'll collapse and go to hospital if I'm lucky' 'Panic - If I don't stop the car this'll get bad and I'll stop breathing - haven't got much time' 'The smoke (*in the pub*) will clog up my lungs and I'll get ill - panic' 'I'll get breathless and pass out' 'Choke' 'I'll need to find a hospital and there may not be one for miles' 'I may have a serious attack, and no-one around knows how to help me' 'I have to get back home - need a phone to get help before I stop breathing'

APPENDIX XIX

Table 20: Test-retest reliability data for 18 participants- Wilcoxon's analysis of anxiety scores, belief in becoming ill, and belief in dying, for each question.

	Anxiety ratings z	Belief in becoming ill z	Belief in dying z
'Safe' items			
Friends house - chest tight	-2.58*	-0.87	-0.27
Stairs/home - hard to breathe	-0.77	-0.53	-0.94
Hospital - tired/exhausted	-1.49	-2.19*	-1.28
With Physio - chest congested	-0.86	-0.53	-0.27
Home with friend - wheeze	-0.15	-0.90	-1.35
GP surgery - cough heavily	-0.49	-0.10	0.00
Garden/friend - short of breath	-0.10	0.00	-0.94
'Unsafe' items			
Smokey pub - chest tight	-0.77	-1.33	-0.42
Stairs at shop - hard to breathe	-2.10*	-1.78	-0.18
Crowd/town - tired/exhausted	-2.04*	-1.12	-1.48
Drive m/way - chest congested	-0.59	-0.18	-0.73
Crowded bus - wheeze	-0.39	-1.02	-0.25
Supermarket - cough heavily	-0.35	-0.51	-0.94
Long walk - short of breath	-0.90	-0.71	-0.28

*$p<0.05$

APPENDIX XX

Figures demonstrating the outlying scores of one participant for ratings of anxiety on 'safe' items on the IBPQ

Figure 1

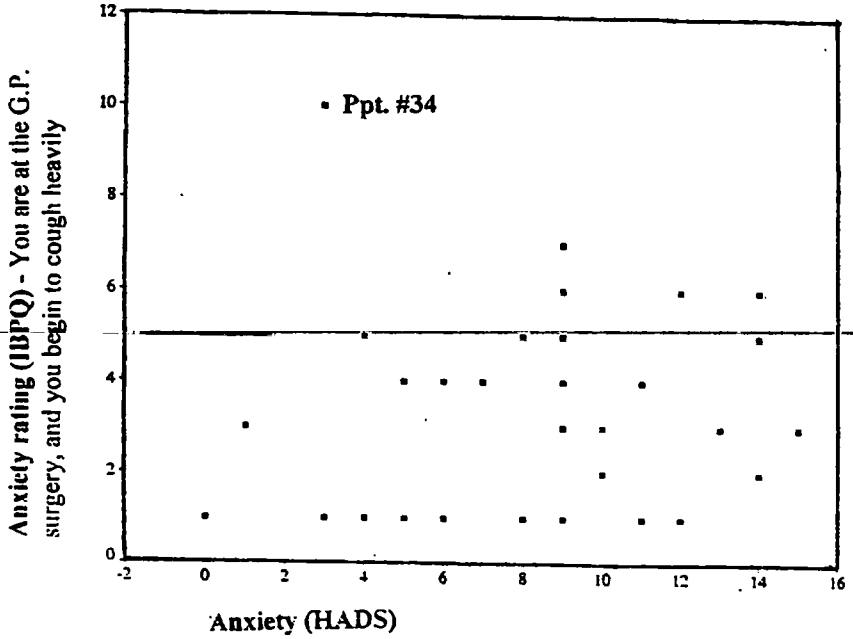


Figure 2

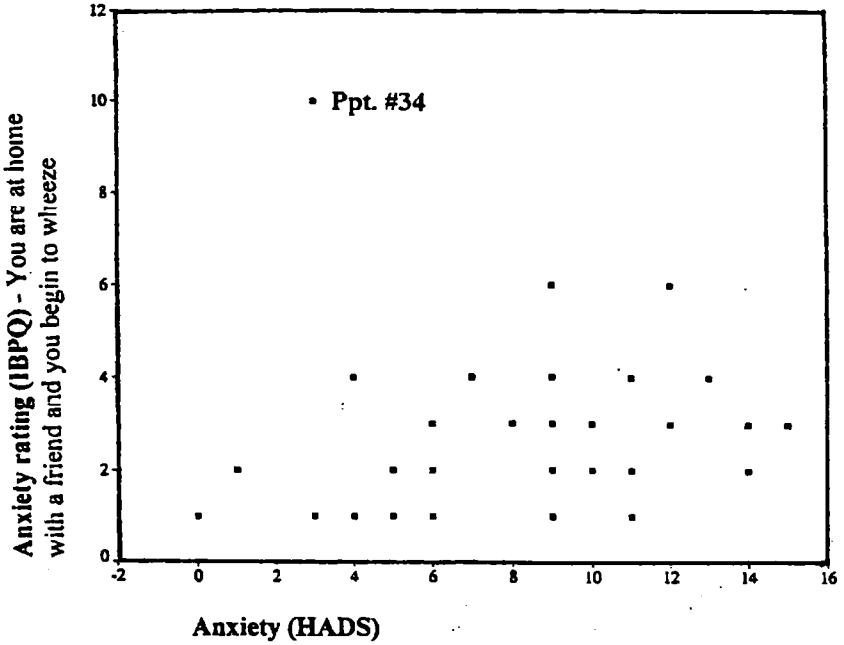
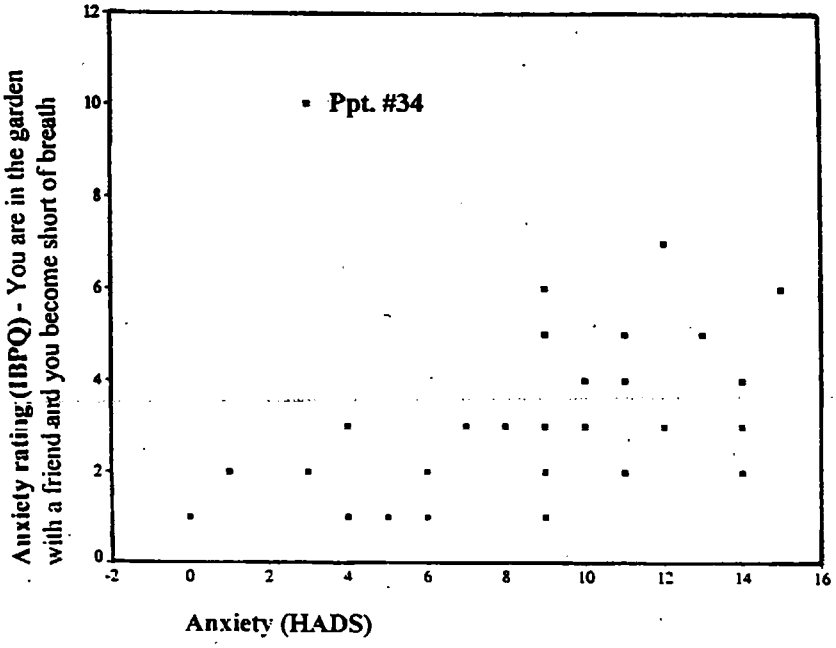


Figure 3


Ppt. #34
Anxiety rating (IBPQ) - You are in the garden with a friend and you become short of breath
Anxiety (HADS)
12
10
8
6
4
2
0
-2
0
2
4
6
8
10
12
14
16

APPENDIX XXI

Table 21: Correlations of anxiety ratings for each question, with individual HADS scores for (i) all 37 participants, and (ii) Excluding outlier.

	All participants (n=37) Correlation Coefficient	Excluding outlier (n=36) Correlation Coefficient
'Safe' items		
Friends house - chest tight	0.32*	0.47**
Stairs/home - hard to breathe	0.21	0.39**
Hospital - tired/exhausted	0.28*	0.32*
With physio - chest congested	0.28*	0.48**
Home with friend - wheeze	0.17	0.43**
GP surgery - cough heavily	0.19	0.36*
Garden/friend - short of breath	0.39**	0.64**
'Unsafe' items		
Smokey pub - chest tight	0.50**	0.58**
Stairs at shop - hard to breathe	0.52**	0.62**
Crowd/town - tired/exhausted	0.40**	0.50**
Drive m/way - chest congested	0.16	0.22
Crowded bus - wheeze	0.47**	0.56**
Supermarket - cough heavily	0.40**	0.52**
Long walk - short of breath	0.42**	0.50**

*$p<0.05$; **$P<0.01$

APPENDIX XXII

Table 22: Construct Validity - Catastrophic thought ratings correlated with ratings of anxiety

	Open-ended responses correlated with ratings of anxiety (n=37) Correlation coefficient
'safe' items	
Friends house - chest tight	0.53**
Stairs/home - hard to breathe	0.68**
Hospital - tired/exhausted	0.51**
With physio - chest congested	0.55**
Home with friend - wheeze	0.62**
GP surgery - cough heavily	0.65**
Garden/friend - short of breath	0.60**
'unsafe' items	
Smokey pub - chest tight	0.59**
Stairs at shop - hard to breathe	0.65**
Crowd/town - tired/exhausted	0.71**
Drive m/way - chest congested	0.32*
Crowded bus - wheeze	0.75**
Supermarket - cough heavily	0.73**
Long walk - short of breath	0.81**

*$p<0.05$; **$p<0.01$

APPENDIX XXIII

Table 23: Concurrent Validity - Correlations of open-ended responses with belief in becoming ill and belief in dying.

	Openended responses for (37 participants) correlated with: Belief/ill Correlation coefficient	Belief/dying Correlation coefficient
'safe' items		
Friends house - chest tight	0.38**	0.36*
Stairs/home - hard to breathe	0.57**	0.55**
Hospital - tired/exhausted	0.33*	0.43**
With physio - chest congested	0.57**	0.71**
Home with friend - wheeze	0.62**	0.52**
GP surgery - cough heavily	0.55**	0.76**
Garden/friend - short of breath	0.54**	0.64**
'unsafe' items		
Smokey pub - chest tight	0.48**	0.49**
Stairs at shop - hard to breathe	0.43**	0.33*
Crowd/town - tired/exhausted	0.70**	0.71**
Drive m/way - chest congested	0.60**	0.57**
Crowded bus - wheeze	0.84**	0.53**
Supermarket - cough heavily	0.69**	0.54**
Long walk - short of breath	0.82**	0.56**

*$p<0.05$; **$p<0.01$